

THIRD EDITION

RESOLVING ETHICAL DILEMMAS

A GUIDE FOR CLINICIANS

Bernard Lo, M.D., F.A.C.P.

Professor of Medicine
Director, Program in Medical Ethics
University of California, San Francisco
Attending Physician, Moffitt-Long Hospital
School of Medicine,
San Francisco, California



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Preface to the First Edition

As a resident, I was paged by the intensive care unit late one night. I recognized the patient, a 17-year-old boy who had undergone bone marrow transplantation for leukemia and now had chronic interstitial fibrosis. The shy, bright smile I remembered from a previous admission was gone. According to the chart, he had developed progressive respiratory failure. His thin intubated body was squirming restlessly in the bed. The patient's father grabbed my hand and pointed to the ventilator, saying, "Stop, it's enough. He doesn't want this." I phoned the attending physician, an eminent hematologist, who said that the patient was expected to die in the next few days. I asked whether we should extubate the patient, as his father had requested, and sedate him. The hematologist said that the bone marrow transplant service wanted to continue intensive care; although he did not defend their decision, he deferred to it. We did agree on a Do Not Resuscitate (DNR) order. I gave some sedation to the patient and tried to comfort him and his family. The boy died just before I went off duty the next morning, more comfortable perhaps but by no means peaceful. The father asked me, "Why didn't they stop? Why?" Later, the attending physician told me that after my phone call, he couldn't get back to sleep. He said that he wanted to call me back to tell me to extubate the patient.

Like this boy's father, I kept asking, "Why?" Why were we so insistent on imposing our medical technology on dying patients? Why were decisions driven by physicians' personalities, hospital politics, research priorities, or staffing problems rather than by what was best for the patient? Why were we comfortable withholding cardiopulmonary resuscitation (CPR) but uneasy administering high doses of narcotics to a patient with intractable ventilatory failure? Although we spent much time on rounds talking about the use of immunosuppressive agents, antibiotics, ventilators, and a vast array of treatments, why did we avoid discussing what to do when such interventions were no longer helpful or appropriate?

My interest in medical ethics, and ultimately this book, grew from such perplexing cases as this and from the illnesses of family members and friends. From visiting my favorite aunt, who had developed multi-infarct dementia, I learned how hard it is to say that life is no longer worth living. She had become almost immobile, dependent on others for all her needs, and would often moan and shout when moved. But she would smile when I held her hands or stroked her cheek. Although mute most of the day, she laughed when I showed her pictures of my son and would ask me, "How old?" We could spend an hour looking at the same pictures over and over, with her repeating the same questions. But even as her family and I despaired over her deteriorating condition, it was not yet time to let her go. Life was still a precious gift, not yet an intolerable burden.

As I began writing and speaking about medical ethics, I learned that many colleagues shared my concerns. At professional meetings practitioners often tell me about cases whose ethical dilemmas still bother them. I have tried to keep in mind such physicians struggling to do what was right in difficult situations. This book features realistic cases that physicians can relate to their own experience. The goal of *Resolving Ethical Dilemmas* is to help clinicians resolve the mundane ethical issues in patient care as well as the dilemmas that keep them awake at night. In some cases there are persuasive reasons for a course of action, but in others the countervailing arguments are equally compelling. Yet even when the philosophic debate is closely balanced, physicians must act, choosing one plan of care or another.

This book grew in several ways beyond my initial work on decisions regarding life-sustaining interventions. First, over the years I realized that physicians need help with many ethical issues. Friends and colleagues often asked me why no one has written about impaired colleagues, about patients' requests to deceive insurance companies, and about the ethical problems in managed care.

Second, as the AIDS epidemic ravaged San Francisco, we grappled with new ethical dilemmas, such as the duty to provide care, access to experimental therapies, and the fear of nosocomial HIV infection. Third, a personal calamity broadened the issues of this book. On October 20, 1991, a firestorm raged through the Oakland hills. Our house and more than 2,000 others burned to the ground in a few hours. My wife and I felt sad, angry, frustrated, and overwhelmed by the task of putting our lives back together. It was hard to make any choices, much less informed or rational ones. Gradually I realized I was struggling with the same issues in this book as in life. Issues of autonomy, informed consent, and fiduciary responsibility took on increasing prominence. How can people make informed decisions when they are emotionally overwhelmed? Why must physicians act in their patients' best interests, even to their personal financial disadvantage, when insurance companies and other businesses have no such obligation?

Colleagues sometimes ask me why I work on such "depressing" topics. Although the issues are indeed somber, it is also a special privilege when patients and their families trust us with their grief, anger, and tranquility and show us how to endure turmoil and sorrow. An elderly patient who had hidden for months the severity of her bone cancer pain was delighted when I made a home visit, saying, "I am so glad I could show you my garden. Now you know why I want to die here, looking at my flowers." Another of my patients died from breast cancer and recurrent pleural effusions. She always cried and moaned as we tapped her effusions, even though she knew that her breathing would be easier. I wondered whether we were hurting her rather than helping her. After her death, I said to her son that it must have been hard for him to care for her. He replied softly, "Doc, it made me a better man." As physicians, we see the worst and the best of people. At times they are helpless and angry and make foolish decisions. But when confronting problems that are too large for them, people often become heroes. Ultimately I hope this book will help patients who struggle with such problems by guiding the physicians who care for them.

Bernard Lo

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Preface to the Third Edition

Clinical ethics needs to keep up with dramatic changes in medical practice, with new research on ethical issues, and new ways of thinking about them. This third edition addresses many new developments.

- New federal health privacy regulations have created new legal obligations and have heightened attention to confidentiality. However, misunderstandings about these regulations have impeded good patient care.
- New research and reports about medical errors have led to new ways of thinking about mistakes, responsibility for errors, and disclosure of errors to patients or families.
- In transplantation the use of live donors (and unrelated live donors) has increased. Although these changes might increase the supply of organs for transplantation, they also heighten concerns about inadequate consent or excessive risk.
- In the wake of the SARS epidemic and anthrax outbreaks, clinicians can expect to face dilemmas when patients refuse to comply with public health recommendations.
- New regulations limiting residents' working hours have led to new dilemmas in teaching hospitals.
- A highly publicized legal case about withdrawing a feeding tube from a woman in a persistent vegetative state has highlighted disagreements over who is the appropriate surrogate for patients who lack decision-making capacity.

This edition also contains important revisions regarding genetic testing, gifts from drug companies, advance directives, and futile interventions. Important new material has been added to the chapters on specialties other than internal medicine. Chapter 37 has more discussion of adolescent confidentiality and consent for care. Chapter 38 discusses disclosure of provider-specific outcomes. Chapter 40 has new material on outpatient commitment and on use of psychiatric medications to enhance mental and social functioning in persons who do not have major psychiatric illness. Finally, the cases for discussion and the accompanying questions have been expanded.

It is a pleasure to thank the many colleagues and friends who have helped me better understand these difficult topics. I owe a special thanks to Leslie Wolf, Steve Pantilat, Sara Swenson, and Doug White, who through many discussions have shared their clear thinking, common sense, and expertise. Patti Zettler provided invaluable background research and skilled editing. David Cox, Elena Gates, and Kim Kirkwood have helped me better understand their respective specialties. Collaborations with Ann Alpers, Tom Bodenheimer, Tom Gallagher, Angela Holder, Mitchell Katz, Timothy Quill, and James Tulsky have enabled me to explore new territory and fresh ideas. Over the years, Nancy Dubler and Robert Steinbrook have been extraordinary friends and colleagues. I have been fortunate to work with thoughtful colleagues on the Greenwall Foundation Faculty Scholars Program, the Recombinant DNA Advisory Committee at the National Institutes of Health, the Institute of Medicine, the National Bioethics Advisory Commission, and the American College of Physicians Ethics Committee and End-of-life Care Panel. I am grateful for the opportunity to learn from them. At UCSF, I have benefited from residents, medical students, and fellows who ask hard questions and share their tough cases. My department chairman, Lee Goldman, has given unstinting support and encouragement. I am grateful to the Greenwall Foundation and the National Institutes of Mental Health for supporting some of the work that formed the basis of this revision.

To my family, I owe my greatest thanks. I am ever grateful to my parents, C.P. and Lucy Lo, and my aunt, Edith Chu, for the values they imparted to me. The physicians in my family, my sister and brother-in-law, Anna and Peter Davol, and my wife, Laurie Dornbrand, have provided shining

An Approach to Ethical Dilemmas in Patient Care

“This case is really bothering me. I haven’t been able to stop worrying about it. I’m just not sure what the right thing to do is.” Cases that have no easy answers can perplex physicians. Strong reasons for a course of action might be balanced by cogent countervailing arguments. Common sense, clinical experience, being a good person, and having good intentions do not guarantee that physicians will respond appropriately to such dilemmas. Ethical dilemmas provoke powerful emotional responses, and strong emotions are often a clue to the presence of an unresolved ethical issue. However, emotions alone are not a satisfactory way of resolving ethical dilemmas. The following cases illustrate the range of ethical issues in clinical medicine.

CASE 1.1 Decisions about life-sustaining interventions.

An elderly woman with severe dementia develops pneumonia. Her daughter insists that hospitalization and administration of antibiotics would be pointless and that the patient would not want such “heroics.” However, her son demands that she be treated because he believes that life is sacred. In this case the physician can be criticized no matter what she does, either for imposing unwanted interventions or for withholding beneficial therapy.

CASE 1.2 Confidentiality of HIV test results.

A 32-year-old man with a positive test for human immunodeficiency virus (HIV) antibodies refuses to notify his wife. “If she finds out, it would destroy our marriage.” Should the physician notify the wife despite the patient’s objections? Although maintaining patient confidentiality is important, it seems cruel not to warn the wife that she is at risk for a fatal infection.

CASE 1.3 Referrals in a managed care system.

A high-school basketball star suffers a knee injury and a probable meniscus tear. She belongs to a particular health maintenance organization (HMO) whose orthopedic surgeons have little experience with arthroscopic surgery. Should the physician tell the patient that more experienced surgeons are available outside the HMO? In this situation the HMO’s financial interest and the physician’s self-interest conflict with the physician’s obligation to act in the patient’s best interests.

In such cases physicians cannot avoid difficult decisions. This chapter describes how clinical ethics can help physicians deal with such dilemmas and presents an approach to resolving them. Specific ethical problems are discussed in detail in subsequent chapters.

WHAT IS CLINICAL ETHICS?

SOURCES OF MORAL GUIDANCE

Personal Moral Values

Physicians, like everyone, draw on many sources of moral guidance, including parental and family values, cultural traditions, and religious beliefs. These are the roots of a person's moral values and create a disposition to do the right actions. However, there are several reasons why they cannot be the only guidance for dilemmas in clinical ethics.

First, these personal moral values might not address important issues in clinical ethics: Often, doctors face many difficult ethical issues for the first time during their training and clinical practice. As shown in Case 1.1, laypeople have little education about such topics as life-sustaining treatment or surrogate decision making. In addition, personal moral values might offer conflicting advice on a particular situation. People often hold several fundamental beliefs that are in conflict. A physician might want both to alleviate the suffering of a dying patient and to respect the sacredness of life. For physicians to be perplexed about a dilemma in clinical ethics is not a blot on their characters or backgrounds.

Second, physicians have role-specific ethical obligations that go beyond their obligations as good citizens and good persons. Doctors have special duties to maintain confidentiality, as seen in Case 1.2, and to disclose information to patients during the informed consent process, as seen in Case 1.3. The moral values and upbringing that guide physicians' personal lives usually do not address special professional roles.

Third, physicians need to persuade others of their plans to resolve ethical dilemmas in patient care. Other health care workers, patients, and family members might have different religious or cultural backgrounds than the patient. Also, patients and their relatives might not understand the physician's professional codes of behavior. Clinical ethics analyzes the reasons that justify a particular course of action. People can be persuaded by cogent arguments, and people with different worldviews can reach an agreement in specific cases. Frequently, positions on ethical issues can be shown to be untenable because they are internally inconsistent or do not take into account countervailing arguments.

We next discuss the general types of justifications commonly offered for actions. Subsequent chapters analyze specific justifications for actions in various situations.

Claims of Conscience

Sometimes people explain their actions as a matter of conscience: to act otherwise would make them feel ashamed or guilty or violate their sense of wholeness or integrity. Conscience involves self-reflection and judgment about whether an action is right or wrong (1). For example, in Case 1.2, a physician might declare, "I couldn't live with myself if I didn't notify his wife."

Deeply held claims of conscience are generally honored. It would be dehumanizing to compel people to act in ways that violate their sense of integrity and responsibility. Claims of conscience, however, might not always resolve a dispute. Other people might cite their own conscience as a countervailing argument. Also, people might sometimes appeal to the conscience to rationalize a selfish or immoral action.

Claims of Rights

To explain their positions on ethical issues, people often appeal to rights, such as a "right to die," or a "right to health care." To philosophers, rights are justified claims that a person can make on others or on society (2). The language of rights is widespread in U.S. culture, yet appeals to rights are often controversial. Other people might deny that the right exists, or they might assert conflicting rights. For example, in Case 1.2, even if the seropositive patient has a right to confidentiality, the wife might have a countervailing right to know that she is at risk for a fatal infectious disease. Claims of rights are often used to end debates; however, the crucial issue is whether persuasive arguments support the existence of the right.

Distinguishing Morality and Ethics

The terms "morality" and "ethics" are often used interchangeably to refer to standards of right and wrong behavior. However, it is helpful to draw some distinctions. Moral choices ultimately rest on values or beliefs that cannot be proved but are simply accepted. Morality usually refers to conduct

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that conforms "to the accepted customs or conventions of a people (3)." A child usually learns from parents and religious leaders what a particular culture or group regards as correct and might accept it without deliberation. Ultimately, such fundamental moral beliefs are part of a person's character. Yet ordinary moral rules, which usually provide an adequate guide for daily conduct, might fail to provide clear direction in many clinical situations. For instance, moral precepts to respect the sanctity of life can be used in Case 1.1 to justify both continuing and withholding antibiotics.

In contrast to morality, ethics connotes deliberation and explicit arguments to justify particular actions. Ethics also refers to a branch of philosophy that deals with the "principles governing ideal human character" or to a professional code of conduct (3). To philosophers, ethics focuses on the reasons *why* an action is considered right or wrong. It asks people to justify their positions and beliefs by rational arguments that can persuade others.

HOW DOES CLINICAL ETHICS DIFFER FROM LAW?

The law, through statutes, regulations, and decisions in specific cases, also provides guidance on what physicians may or may not do. On many issues the law reflects an ethical consensus in society. Moreover, rulings by courts give reasons for decisions and therefore provide an analysis of pertinent issues. Hence, physicians should be familiar with what the law says regarding issues in clinical ethics. However, the law cannot provide definitive answers to ethical dilemmas.

First, the law, particularly the criminal law, sets only a minimally acceptable standard of conduct. It indicates what acts are so *wrong* that the physician will be held legally liable for committing them. In contrast, ethics focuses on the *right* or the best decision in a situation. From a legal perspective, pediatricians need only obtain the authorization of the parent or guardian to treat a child. However, professional ethics requires pediatricians to provide pediatric patients with pertinent information in ways that are developmentally appropriate and to obtain their assent for care (*see* Chapter 37). Furthermore, ethical standards require pediatricians to act with compassion and integrity; it is impossible for the law to enforce such standards. Second, the law explicitly grants physicians discretion in some situations. For instance, most states allow physicians to determine when a patient lacks decision-making capacity and, thus, when a surrogate should take over the role of making decisions with the physician (*see* Chapter 13). In these states, physicians must act on ethical and clinical considerations, not legal ones. Third, the law might provide no clear guide to action on certain topics. For example, the law provides scant guidance on the issue of disclosing genetic information to relatives when the patient objects to disclosure. Finally, law and ethics might conflict. Abortion is legal throughout the United States, and physician-assisted suicide is legal in the state of Oregon. However, both practices continue to be controversial ethically.

Furthermore, many people might regard actions that are prohibited by law to be ethical. In a few states the courts have rejected family decision making for incompetent patients who have not provided written advance directives or very specific oral directives. Ethically, however, the consensus is to respect surrogate decision making by concerned family members (*see* Chapter 12). In such conflicts, most physicians feel uncomfortable about simply following the letter of the law.

HOW DOES CLINICAL ETHICS DIFFER FROM PROFESSIONAL OATHS AND CODES?

Many physicians seek ethical guidance from professional codes, such as the Hippocratic Oath or the modern codes of ethics of the American Medical Association or the American College of Physicians (4,5). Although professional oaths and codes might provide helpful guidance for physician behavior, they have several shortcomings (6). First, they are unilateral declarations by groups of physicians, without any input from patients or the public. Codes of ethics and professional oaths do not acknowledge that society has granted autonomy and privileges to physicians and, therefore, has the right to insist on certain expectations. Second, the content of professional codes has been criticized. The Hippocratic tradition is highly paternalistic, granting patients little role in making decisions. For instance, it does not require physicians to disclose information to patients or allow them to make informed choices. Nor does the Hippocratic Oath enjoin physicians to be truthful with patients. Third, oaths and codes are often terse documents that articulate general precepts but fail to address many specific ethical issues. Resolving difficult cases generally requires additional analysis beyond such general guidance.

HOW CLINICAL ETHICS CAN HELP PHYSICIANS

Certain situations commonly recur in clinical practice. Physicians learn to recognize individual cases as examples of syndromes, such as "angina" or "hyponatremia (7)." Placing cases into categories allows physicians to organize relevant data and draw on experiences with similar cases. For each type of case, the physician learns to gather additional information, to anticipate associated problems or complications, and to develop an approach to the class of cases. To be sure, the approach needs to be modified in specific cases, because no two cases are identical and there are always exceptional cases. Nonetheless, a standard approach can manage the vast majority of cases. The more categories of cases physicians have studied, the better prepared they are for clinical practice.

Learning about clinical ethics can help physicians identify, understand, and resolve common ethical issues in patient care. By studying "teaching cases," physicians can gain vicarious experience in resolving specific dilemmas (8,9). Doctors can learn how to interpret ethical guidelines in particular situations, how to identify features of a case that distinguish it from other apparently similar cases, and how to know when exceptions to guidelines are justified.

IDENTIFY ETHICAL ISSUES

By studying realistic cases that illustrate common ethical problems, physicians may better recognize the ethical issues in their own cases. In some cases physicians might have only a vague uneasiness that important ethical issues are at stake. In other situations health care workers might be perplexed about difficult decisions but fail to identify problems as specifically ethical in nature, as opposed to issues of clinical management or interpersonal conflict. Thus, physicians need to be able to identify such fundamental ethical issues as assessment of decision-making capacity, advance directives, or confidentiality and to develop an approach to each issue.

UNDERSTAND AREAS OF ETHICAL CONSENSUS AND CONTROVERSY

On many issues, physicians, philosophers, and the courts agree on what should be done (6,10-12). Such agreement is often possible even when people disagree on the reasons for their actions (13). For example, it is well established that competent, informed patients may refuse interventions recommended by their physicians and that certain exceptions to confidentiality of medical information are appropriate both ethically and legally. Subsequent chapters point out areas of widespread ethical agreement as well as those areas of ongoing controversy.

Clinical ethics can indicate which actions are clearly right or wrong and which are controversial. Philosophers distinguish among actions that are obligatory, permissible, and wrong (14). In Case 1.3, it would be *obligatory* for physicians to tell the patient about other options for care (see Chapter 40). At the other extreme, it would be *wrong* for physicians to lie and tell the patient that the orthopedic care in this HMO is as good as the care elsewhere. Still other actions might be ethically *permissible* but not required. Some acts may be optional because the arguments for and against them are so evenly balanced that reasonable people may disagree. Other actions are optional in a different sense: It would be praiseworthy to perform them, but failure to do so would not be blameworthy. For instance, it would be heroic for a busy physician in Case 1.3 to devote extensive time to convincing the HMO to pay for orthopedic care outside the system, but he could not be blamed if he merely wrote a letter and made some phone calls on the athlete's behalf.

AN APPROACH TO ETHICAL DILEMMAS IN CLINICAL MEDICINE

A systematic approach to ethical problems helps ensure that no important considerations are overlooked and that similar cases are resolved consistently. The approach outlined in Table 1-1 includes three general steps: clarifying the facts of the case, analyzing the ethical issues, and resolving the dilemma. For any particular case, an experienced physician may modify the general approach.

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ANALYZE THE ETHICAL ISSUES

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TABLE 1-1

An Approach to Ethical Dilemmas in Clinical Medicine

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- Clarify the facts of the case.
 - What is the clinical situation?
 - Who is the primary decision maker?
 - What are the concerns, values, and preferences of stakeholders?
 - Analyze the ethical issues.
 - What are the pertinent ethical issues?
 - How should ethical guidelines be applied to these issues?
 - Address psychosocial issues.
 - What pragmatic issues complicate the case?
 - Hold a team meeting.
 - Meet with the patient or family.
 - Negotiate to reach agreement.
 - Seek assistance as needed.
-

CLARIFY THE FACTS OF THE CASE

Physicians first need to gather pertinent information about the medical situation and the ethical issues in the case.

What Is the Clinical Situation?

Sound ethical decision making requires accurate clinical information about the patient's diagnosis and prognosis, the options for care, and the benefits and risks of each alternative. In addition, psychosocial information is essential, such as the relationships among patient, son, and daughter in Case 1.1 or between the husband and wife in Case 1.2.

Who Is the Primary Decision Maker?

If the patient is competent, he or she makes decisions jointly with the physician, choosing among feasible alternatives. If the patient lacks decision-making capacity, an appropriate surrogate needs to be identified, generally a family member. Case 1.1 illustrates disagreements over who should serve as surrogate. Physicians need to understand the preferences of the patient or surrogate, as well as the reasoning behind their choices.

What Are the Concerns, Values, and Preferences of Stakeholders?

Other health care workers who provide direct care to the patient need to be involved in decisions. Nurses, house staff, and medical students are responsible for their actions when carrying out the attending physician's "orders." In addition, these health care workers have close relationships with patients and families, answer their questions, and explain plans for care. Other people might also have a stake in decisions. In Case 1.2, the patient's wife will be directly affected by the decision. Her viewpoint needs to be taken into account.

ANALYZE THE ETHICAL ISSUES

What Are the Pertinent Ethical Issues?

As with clinical medicine, how a case is framed often determines how it is resolved. Case 1.1 could be framed as a family disagreement. However, it is more fruitful to focus on more specific ethical issues:

- Has the patient provided trustworthy advance directives? (*See* Chapter 12.)
- Who should serve as surrogate decision maker for incompetent patients? (*See* Chapter 13.)

How Should Ethical Guidelines Be Applied to These Issues?

Framing ethical issues properly often suggests considerations to be taken into account and an approach to the situation. In Case 1.1, there are well-established guidelines to help the physicians and family determine what weight to give the patient's previous statements. If the patient had given trustworthy advance directives, they should be respected. People might agree on ethical guidelines but disagree over how to interpret them. For example, the son might agree with respecting the patient's choices but argue that her previous statements were too ambiguous to direct care. In Case 1.2, maintaining patient confidentiality conflicts with preventing harm to another person. Existing guidelines help the physician determine whether overriding confidentiality is justified in this situation (*see* Chapter 5). In Case 1.3, if the physician's arrangement with a managed care plan includes a "gag clause" that forbids her from disclosing interventions not covered by the plan, such clauses are considered unethical (*see* Chapter 6).

Difficult cases cannot be resolved by mechanically applying formal rules. Discretion and practical judgment are needed to interpret general guidelines in the particular circumstances of a case or to consider other factors.

ADDRESS PSYCHOSOCIAL ISSUES

Although analysis of ethical issues is essential, few dilemmas in clinical ethics are resolved solely by philosophical arguments. Good communication and interpersonal skills are also needed.

What Pragmatic Issues Complicate the Case?

Emotions, misunderstandings, interpersonal conflicts, and time pressures often complicate clinical dilemmas. Physicians need to identify and address such complicating factors. Indeed, many "ethical" dilemmas are settled by addressing these issues rather than through philosophical debate. Showing respect, concern, and compassion builds trust and helps resolve dilemmas.

Hold a Team Meeting

Team meetings can provide additional information about the patient's medical condition and the views of stakeholders. Health care workers from different clinical, personal, and cultural backgrounds can frequently point out hidden assumptions and value judgments, call attention to neglected issues, and suggest fresh alternatives. Moreover, a team meeting offers the opportunity to forge agreement on recommendations for care.

Meet with the Patient or Family

Physicians need to talk to patients and families to understand their concerns, needs, and values. Open-ended questions can elicit their perspective. In Case 1.1, the physician can ask, "As you think about your mother's condition, what concerns you the most? What do you hope for?" If such concerns can be addressed directly, the patient or family often accepts the physician's recommendations.

Patients or families might become confused if they hear mixed messages from different clinicians. Family conferences with all health care workers enhance consistent communication. If the health care team cannot agree on recommendations, the areas of agreement and disagreement need to be articulated carefully.

NEGOTIATE TO REACH AGREEMENT

Physicians need to try to reach a decision that is acceptable to both them and the patient or surrogate. Decisions also need to be consistent with the ethical guidelines discussed in this book and in the medical literature. To achieve this, physicians need to be flexible and be willing to compromise.

SEEK ASSISTANCE AS NEEDED

In difficult cases the physician may seek assistance from the hospital ethics committee or an ethics consultant (*see* Chapter 16). A second opinion from another physician not directly involved in the case might also be helpful. A chaplain, social worker, or nurse might have better rapport with the patient or family than the physician and be able to facilitate discussions.

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In summary, physicians commonly face difficult ethical issues in clinical practice. Reading about such issues, thinking about them, and discussing them with colleagues can help physicians resolve ethical dilemmas. As with any clinical problem, following a systematic approach helps ensure that all pertinent considerations are taken into account. The important steps include gathering information about the medical situation and the preferences of the patient or surrogate and clarifying the salient ethical and pragmatic issues.

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Overview of Ethical Guidelines

In clinical medicine ethical dilemmas arise because there are sound reasons for conflicting courses of action. In resolving ethical dilemmas, physicians need to refer to general maxims that inform choices and justify actions. This chapter provides an overview of guidelines in clinical ethics. Subsequent chapters discuss these ethical guidelines in detail and apply them to specific cases.

RESPECT FOR PERSONS

Treating patients with respect entails several ethical obligations. First, physicians must respect the medical decisions of persons who are autonomous (1). The term *autonomy* literally means “self-rule.” Autonomous people act intentionally, are informed, and are free from interference and control by others. They should be allowed to shape their lives and control their destinies. The concept of autonomy includes the ideas of self-determination, independence, and freedom. In addition to respecting the decisions of autonomous patients, doctors should take steps to promote patient autonomy, as by disclosing information and helping patients deliberate.

With regard to health care, autonomy justifies the doctrine of informed consent (see Chapter 3). Informed consent has several specific aspects. Informed, competent patients may refuse unwanted medical interventions. In the case of surgery and invasive procedures, such refusals respect patients’ bodily integrity. In addition, patients may choose among medically feasible alternatives. Important clinical choices need not involve a major bodily invasion. For instance, choosing whether to have an x-ray or choosing among several drugs for a condition do not implicate the patient’s bodily integrity in a manner similar to surgery. Competent, informed patients have the right to make choices that conflict with the wishes of family members or the recommendations of their physicians.

A person’s autonomy is not absolute and may be justifiably restricted for several reasons. If a person is incapable of making informed decisions, trying to respect his or her autonomy might be less important than acting in his or her best interests. Autonomy might also be constrained by the needs of other individuals or society at large. A person is not free to act in ways that violate other people’s autonomy, harm others, or impose unfair claims on society’s resources.

A second meaning of respect for persons goes beyond respecting autonomy. Many patients are not autonomous because illness or medication impairs their decision-making capacity. Physicians should still treat them as persons with individual characteristics, preferences, and values. Decisions should respect their preferences and values, so far as they are known. In addition, all patients, whether autonomous or not, should be treated with compassion and dignity. Thus, respect for persons includes responding to the patient’s suffering with caring, empathy, and attention.

Third, respect for persons is related to other ethical guidelines, such as avoiding misrepresentation, maintaining confidentiality, and keeping promises. Breaches of these other guidelines show

Overview of Ethical Guidelines

disrespect for patients and for these other guidelines.

MAINTAIN CONFIDENTIALITY

Maintaining confidentiality respects people to whom physicians owe a duty. It protects patients’ privacy, preference, or ability to keep medical information confidential. In some situations, it protects patients from harm (e.g., discrimination).

AVOID DECEPTION

Truth telling—on the part of physicians to others and on the part of others to tell the physician—is a duty. It is not deceptive. Deception is to make decisions based on false information. Deception is a form of “deception” that is not about truth or falsehood. It is about bad news. It is not about truth or falsehood.

KEEP PROMISES

Physicians generally keep promises with patients. It is unfair to break promises. Furthermore, patients will not accept promises that are not kept.

ACT IN THE BEST INTERESTS OF THE PATIENT

The guideline of acting in the best interests of the patient is a guideline of last resort. It is only when a patient is not autonomous, or when a patient is not acting in his or her best interests, that a physician should act in the best interests of the patient. The guideline of acting in the best interests of the patient is a guideline of last resort. It is only when a patient is not autonomous, or when a patient is not acting in his or her best interests, that a physician should act in the best interests of the patient.

UNWISE DECISIONS

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disrespect for patients and also compromise their self-determination. There are additional reasons for these other guidelines, as we will discuss.

MAINTAIN CONFIDENTIALITY

Maintaining the confidentiality of medical information respects patient privacy. It also encourages people to seek treatment and to discuss their problems frankly. In addition, confidentiality protects patients from harms that might occur if information about psychiatric illness, sexual preference, or alcohol or drug use were widely known. Patients and the public expect physicians to keep medical information confidential. Maintaining confidentiality, however, is not an absolute duty. In some situations physicians need to override confidentiality in order to protect third parties from harm (*see* Chapter 5).

AVOID DECEPTION AND NONDISCLOSURE

Truth telling—avoiding lies—is a cornerstone of social interaction. If people cannot depend on others to tell the truth, no one will make agreements or contracts. Physicians also might mislead patients without technically lying, for example, by giving partial information that is literally true but deceptive. Deception violates the autonomy of people who are deceived because it causes them to make decisions on the basis of false premises. To cover these broader issues, this book uses the term “deception” rather than “lying.” In addition, physicians may withhold from patients information about their diagnosis or prognosis. Physicians may withhold information to protect patients from bad news. However, patients cannot make informed decisions about their medical care if they do not receive the information about their condition that they would like to have.

KEEP PROMISES

Promises generate expectations in other people, who in turn modify their plans on the assumption that promises will be kept. The very concept of promises is undermined if people are free to break them. It is unfair for someone to expect others to honor their promises, but to break his or her own. Keeping promises also enhances trust in both the individual physician and the medical profession. Furthermore, promises relieve patients’ anxiety about the future by providing reassurance that doctors will not abandon them.

ACT IN THE BEST INTERESTS OF PATIENTS

The guideline of nonmaleficence, or “do no harm,” forbids physicians from providing ineffective therapies or from acting selfishly or maliciously (2). This oft-cited precept, however, provides only limited guidance, because many beneficial interventions also entail serious risks and side effects. Literally, doing no harm would preclude such treatments as surgery and cancer chemotherapy.

The guideline of *beneficence* requires physicians to take positive actions for the benefit of patients (*see* Chapter 4). Because patients do not possess medical expertise and might be vulnerable owing to illnesses, they rely on physicians to provide sound advice and to promote their well-being. Physicians encourage such trust. For these reasons, physicians have a fiduciary duty to act in the best interests of their patients.

UNWISE DECISIONS BY PATIENTS

Acting in patients’ best interests might conflict with respecting their informed choices, as when patients’ refusals of care might thwart their own goals or cause them serious harm. For example, a young man with asthma may refuse mechanical ventilation for reversible respiratory failure. Simply accepting such refusals, in the name of respecting autonomy, would constitute a constricted view of responsibility. Physicians need to listen to patients, educate them, try to persuade them to accept beneficial treatment, or negotiate a mutually acceptable compromise. If disagreements persist, the patient’s informed choices and view of best interests should prevail.

PATIENTS WHO LACK DECISION-MAKING CAPACITY

The choices and preferences of many patients who lack decision-making capacity are unknown or unclear. In this situation, respecting autonomy is not pertinent. Instead, physicians should be guided by the patient's best interests (*see* Chapter 4).

CONFLICTS OF INTEREST

Physicians should act in the patient's best interests rather than in their own self-interest when conflicts of interest occur (*see* Chapters 29–36). Patients trust their physicians to act on their behalf and feel betrayed if that trust is abused. In a potential conflict of interest, physicians should consider how patients, the public, and colleagues would react if they knew about the situation. Even the appearance of a conflict of interest might damage trust in the individual physician and in the profession.

ALLOCATE RESOURCES JUSTLY

The term “justice” is used in a general sense to mean fairness—that is, people should get what they deserve. In addition, people who are situated equally should also be treated equally. It is important to act consistently in cases that are similar in ethically relevant ways. Otherwise, decisions would be arbitrary, biased, and unfair. More precisely, people who are similar in ethically relevant respects should be treated similarly, and people who differ in ethically significant ways should be treated differently. To make this formal statement of justice operational, the physician would need to specify what counts as an ethically relevant distinction and what it means to treat people similarly.

In health care settings, “justice” usually refers to the allocation of health care resources. Allocation decisions are unavoidable because resources are limited and could be spent on other social goods, such as education or the environment, instead of on health care. Ideally, allocation decisions should be made as public policy and set by government officials or judges, according to appropriate procedures. Physicians should participate in public debates about allocation and help set policies. In general, however, rationing medical care at the bedside should be avoided because it might be inconsistent, discriminatory, and ineffective. At the bedside, physicians usually should act as patient advocates within constraints set by society and sound practice (*see* Chapter 30). In some cases, however, two patients might compete for the same limited resources, such as physician time or a bed in intensive care. When this occurs, physicians should ration their time and resources according to patients’ medical needs and the probability and degree of benefit.

THE USE OF ETHICAL GUIDELINES

Having summarized guidelines for clinical ethics, we next discuss how physicians should use them in specific cases. This book uses the term *guidelines* to connote that ethical generalizations cannot be mechanically or rigidly applied but need to be used in particular cases with discretion and judgment. Guidelines are derived from decisions made in specific cases as well as from moral theories (3,4). In turn, guidelines shape decisions in similar cases in the future. However, guidelines might be difficult to apply in new cases for several reasons.

GUIDELINES NEED TO BE INTERPRETED IN THE CONTEXT OF SPECIFIC CASES

The meaning or force of a guideline might not be clear in a particular case. Uncertainty and case-by-case variation are inherent in clinical medicine. Furthermore, patients have different priorities and goals for care. A crucial issue is whether the case to be decided can be distinguished in ethically meaningful ways from previous cases to which the guideline was applied. Unforeseen or novel cases might point out the shortcomings of an existing guideline and suggest that it needs to be modified or an exception made.

Overview of

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EXCEPTIONS TO GUIDELINES MIGHT BE APPROPRIATE

Guidelines are not absolute. A particular case, particularly unforeseen or novel cases, might have distinctive features that justify making an exception to a guideline (3). To ensure fairness, physicians who make an exception to a guideline should justify their decisions. The justification should apply not only to the specific case under consideration but also to all similar cases faced by other physicians. Some philosophers regard guidelines simply as rules of thumb that provide advice but are not binding. However, if people can set aside guidelines too easily, decisions might be inconsistent. Many philosophers regard ethical guidelines as *prima facie* binding: They should be followed unless they conflict with stronger obligations or guidelines or unless there are compelling reasons to make an exception (5). *Prima facie* guidelines are more binding than mere rules of thumb. The burden of proof is on those who claim that an exception to the guideline is warranted. Furthermore, when *prima facie* guidelines are overridden, they are not simply ignored. People often experience regret or even remorse that guidelines are being broken. Thus, people should minimize the extent to which *prima facie* guidelines are violated and mitigate the adverse consequences of doing so.

DIFFERENT GUIDELINES MIGHT CONFLICT

In many situations following one ethical guideline would require the physician to compromise another guideline. Respecting a patient's refusal of treatment might clash with acting in the patient's best interests. Maintaining confidentiality might conflict with protecting third parties from harm. Allocating resources equitably might conflict with doing what is best for an individual patient. The practice of medicine would be much easier if there were a fixed hierarchy of ethical guidelines—for example, if patient autonomy always took priority over beneficence. However, life is not so simple. In some clinical situations, respecting a patient's wishes should be paramount, whereas in others a patient's best interests should prevail. Physicians need to understand why an ethical guideline should take priority in some situations but not in others.

The ability to make prudent decisions in specific situations has been described as *discernment* or *practical wisdom*. Discernment involves an understanding of how ethical guidelines are relevant in a variety of situations and to the particular case at hand (6).

PRINCIPLES, RULES, AND DUTIES

This book uses the term guidelines to refer to ethical generalizations that guide action, because other terms, such as principles, rules, and duties, have undesirable connotations. According to the dictionary, *principle* connotes a "basis for reasoning or a guide for conduct or procedure (7)." Many philosophers, however, use the term in a more restricted sense, to refer only to a comprehensive ethical theory that explains how to resolve conflicts among different precepts (8,9). A unified theory would also presumably provide clear, specific rules for action and a justification of those rules (8).

Philosophers have devoted considerable effort to developing comprehensive ethical theories. The two main types of ethical theory are consequentialist and deontological. *Consequentialist* theories judge the rightness or wrongness of actions by their consequences. Utilitarianism, the most prominent consequentialist theory, considers actions and rules appropriate when the overall benefits to all parties outweigh the overall harms. For instance, a utilitarian would consider it justified to tell a lie, breach confidentiality, or break a promise if, on the whole, the benefits of doing so outweigh the harms. In contrast, *deontological* theories claim that the rightness or wrongness of an action depends on more factors than the consequences of an action. To a deontologist, actions such as telling a lie, breaching confidentiality, and breaking promises are inherently wrong. They would be morally suspect even if they produced no harmful consequences or led to beneficial ones.

Comprehensive theories of clinical ethics, however, are problematic (10). Utilitarian theories are flawed because they condone seemingly harmful actions that are not detected. For example, utilitarians might condone breaking a promise when no one else knows it is broken. Furthermore, acts that maximize the benefits for society as a whole may be considered acceptable even though

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they impose grave harms on individual persons. In a utilitarian analysis, harms to individuals might be outweighed by a sufficiently large benefit to society. Such an inequitable distribution of benefits and harms might be unfair.

Deontological theories can be criticized because they cannot provide a satisfactory account of which principles or rules take priority over others in cases of conflict. For example, deontological theories would have difficulty determining whether beneficence or confidentiality would prevail when a patient with human immunodeficiency virus (HIV) infection refused to notify his wife that she is at risk.

Detailed and lucid expositions of ethical theories as well as their critiques are available (10). Many writers, myself included, believe that a comprehensive and consistent theory of clinical ethics cannot be developed (11). This book avoids reference to ethical theories and to the term principle not only because of these conceptual problems but also because ethical theories and principles are too abstract to provide guidance to physicians in specific cases.

The term *rule* is used in ethics to refer to generalizations that are narrower in scope than principles. The term is helpful because it focuses on individual conduct in specific situations, rather than on abstract generalizations. However, rules are generally regarded as binding, often prohibiting certain behaviors (3). In common language, "rule" might imply restrictions on individual conduct in order to maintain order in the group or for the sake of a goal (7). For example, we speak of rules for a game or for an institution. The implication might be that rules can be applied in a straightforward manner, as when disputes in a game are settled by referring to the rules. In this sense, rules may be arbitrarily imposed in order to establish clear expectations for everyone. For example, rules for visiting hours may be established in a hospital to provide clear guidance for conduct, without any claim that one choice of hours is superior to another. However, the term "rule" is misleading in clinical ethics, because exceptions need to be made and because guidelines are not arbitrary conventions but reflect deeply held values.

Finally, this book avoids the term *duty*, which might connote legal as well as ethical obligations. Ethical obligations, however, differ from legal duties imposed by legislation, regulations, or court rulings, as Chapter 22 discusses.

OTHER APPROACHES TO ETHICS

Because ethical theories and principles often do not help people resolve conflicts, other approaches to clinical ethics have been suggested (10,11).

CASUISTRY

Instead of constructing or relying on theories, some writers focus on how to resolve specific cases (3,12–14). According to these writers, people resolve dilemmas in everyday life by "looking at the concrete details of particular cases (15)." In this view, moral rules are not absolute; they merely create presumptions that may be rebutted, depending on the particular circumstances. The strategy is to compare a given case with clear-cut, paradigmatic cases. The key issue is whether the given case so closely resembles the paradigmatic case that it should be resolved in a similar manner or whether it can be distinguished and therefore treated differently (3). In some cases the application of ethical maxims will be clear-cut. In more difficult cases it might be unclear whether a guideline applies or different guidelines might provide conflicting advice. Proponents of case-based ethics emphasize the need for what Aristotle called practical wisdom, the ability to make appropriate decisions given the particular circumstances of the case. The essential issue is "how closely the present circumstances resemble those of the earlier precedent cases for which this type of argument was originally devised (16)." In educational terms, casuistry teaches by case analyses, starting with paradigmatic cases in which principles clearly apply and moving to complex, ambiguous cases over which reasonable people may disagree.

A case-based approach to clinical ethics takes into account the complexity of real-life decisions and offers readers a vicarious experience in resolving ethical problems (17). Dilemmas in clinical ethics generally present as specific decisions in patient care, not as clashes of abstract philosophical principles. This book emphasizes how to approach difficult cases and how to weigh different considerations in reaching a decision.

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AN ETHIC OF

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VIRTUE ETHICS

Some writers point out that Physicians might have a different perspective on the view. The virtue ethics is dedication, and in situations, the physician ethics also has several circumstances that conflict with each other. It demonstrates the possibility of an exception to the rule.

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Case-based analyses, however, face a serious challenge: to provide a convincing basis for weighing some factors more heavily than others in reaching a decision. Indeed, casuistry runs the risk of *ad hoc* reasoning and inconsistent decisions. To avoid such pitfalls, this book will continually refer back to the ethical guidelines described in this chapter and explain why particular factors will be decisive in some situations, while different considerations will weigh most heavily in other circumstances.

AN ETHIC OF CARING

Feminist writers argue that principles and rules provide an incomplete and inadequate conception of ethics (18,19). In this perspective, rule-based morality gives insufficient attention to maintaining or restoring relationships among individuals and avoiding interpersonal conflicts. In this view, responding to the needs and welfare of specific individuals might be more important than acting in accord with abstract standards. For example, when family members make decisions for an incompetent patient, traditional ethics might undervalue the need for the family members to get along with one another and live with the consequences of their decisions (20). In some situations it might be more important to prevent serious family disputes than to follow the patient's prior directives. Such caring and responsiveness is often claimed to be a typically "feminine" orientation, as contrasted with a "masculine" orientation toward rules and principles. Empirical studies, however, do not support the hypothesis of gender-related orientations to ethics (21).

The emphasis on caring and on the well-being of others is welcome in medicine and other helping professions. Caring is essential in the doctor-patient relationship, and sympathy and compassion might be more important in clinical practice than following ethical guidelines mechanically. However, it is also important to move beyond a sensitivity to these issues to a detailed description of how caring should impact on decisions in specific clinical situations. Furthermore, attending to the welfare of others might conflict with other important ethical imperatives, such as respecting the patient's autonomy.

VIRTUE ETHICS

Some writers point out that merely following guidelines might lead to a thin view of ethics. Physicians might perform the right actions but lack the spirit that should animate the medical profession. Virtue ethics emphasizes that the physician's characteristics are ultimately more important than the doctor's specific actions and their congruence with ethical principles (17). In this perspective the essential questions are: Is the doctor a good physician? A good person? In one such view, the virtues of a good physician include fidelity, compassion, fortitude, temperance, integrity, and self-effacement (17).

Virtue ethics is helpful because it emphasizes the importance of such qualities as compassion, dedication, and altruism in physicians. Furthermore, in some extremely complicated or unique situations, the physician's integrity might be a crucial factor in resolving dilemmas. However, virtue ethics also has serious limitations because it lacks specifics on what the doctor should do in particular circumstances. A virtuous person might still commit wrong actions. Also, virtues might conflict with each other. In a given case, some people may believe that following a general guideline demonstrates the physician's integrity, while others believe that it would be compassionate to make an exception to the guideline.

In summary, ethical guidelines include showing respect for persons, avoiding deception, maintaining confidentiality, keeping promises, acting in the best interests of patients, and allocating resources justly. These guidelines need to be applied to particular cases with discretion and judgment. Subsequent chapters discuss these guidelines in detail.

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Informed Consent

Informed consent requires physicians to share decision-making power with patients. Many physicians, however, are skeptical about informed consent or are even hostile to it. Some believe that it is impossible because patients can never understand medical situations as well as doctors. Other physicians regard informed consent as a meaningless legal ritual because they can almost always persuade patients to follow their recommendations. In addition, some patients do not want to participate in decision making, as in the following case.

CASE 3.1 Reluctance to make a decision.

Mr. T was an 88-year-old man with severe chronic obstructive pulmonary disease (COPD), coronary artery disease, and peptic ulcer disease. He developed an adenocarcinoma of the lung, which could be treated with surgery or radiation therapy. His physician was reluctant to recommend surgery because of the patient's increased operative risk. In addition, his COPD was so severe that he might be dyspneic after a pneumonectomy. When his doctor discussed alternatives for treatment, Mr. T said, "Do what you think is best. You're the doctor."

In this case only Mr. T can determine if the chance of being cured of cancer is worth the risk of severe dyspnea, but Mr. T apparently does not want to make decisions. How should the physician proceed? This chapter discusses the definition of informed consent, its justification, its requirements, problems with informed consent, and ways in which physicians can promote shared decision making with patients.

WHAT IS INFORMED CONSENT?

Discussions about informed consent are often confusing because people use this term in different senses.

AGREEMENT WITH THE PHYSICIAN'S RECOMMENDATIONS

Patients usually agree with physicians' recommendations. Such an agreement is particularly common in an acute illness, when the goals of care are clear, one option is superior, the benefits are great, and the risks are small. For example, a patient who suffers a wrist fracture almost always agrees to a cast. In such situations informed consent seems tantamount to obtaining the patient's agreement to the proposed intervention. Physicians often speak of "consenting the patient," implying that it is a foregone conclusion that the patient will agree.

RIGHT TO REFUSE INTERVENTIONS

Another view of informed consent is that patients have an ethical and legal right to be free of unwanted medical interventions. Hence, competent patients have the power to reject their physicians' recommendations about care.

CHOICE AMONG ALTERNATIVES

A broader view of informed consent holds that patients should have the positive right to choose among feasible options in addition to the negative right to refuse unwanted interventions. For instance, Case 3.1 involves not only the right to refuse surgery but also a choice between surgery and radiation therapy.

SHARED DECISION MAKING

A still more comprehensive view is that informed consent is a process of shared decision making by the physician and patient (1). Both parties need to discuss the issues and reach a mutually acceptable decision. Through repeated discussions, physicians can educate patients about their conditions and the alternatives for care, help them deliberate, make recommendations, and to try to persuade them to accept the recommendations (2).

REASONS FOR INFORMED CONSENT AND SHARED DECISION MAKING

Several ethical and pragmatic reasons justify a broader conception of informed consent (3–5).

RESPECT PATIENT SELF-DETERMINATION

People want to make decisions about their bodies and health care in accordance with their values and goals. Decision-making power in health care is important because the stakes can be high. One court expressed this idea in sweeping terms, declaring, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body (6)."

Patient choice should be promoted because in most clinical settings, different goals and approaches are possible, outcomes are uncertain, and an intervention might cause both benefit and harm (7). Individuals place different values on health, medical care, and risk. Some patients are wary about the side effects of medication, while others want to try risky therapies that promise better outcomes. Lung cancer patients are generally concerned about the short-term morbidity and mortality of surgery as well as long-term survival and cure (8). Older patients often prefer radiation therapy, which has a lower 5-year survival rate but also a lower likelihood of death during treatment. Physicians cannot accurately predict patients' preferences. For example, patients with newly diagnosed cancer are more likely than physicians, nurses, and the general public to prefer intensive chemotherapy with little chance of cure (9).

ENHANCE THE PATIENT'S WELL-BEING

The goal of medical care is to enhance patient well-being, which can be judged only in terms of the patient's goals and values. The patient's values are particularly important when various treatment approaches have very different characteristics or complications and involve trade-offs between short-term and long-term outcomes, when one of the options carries a small chance of a grave outcome, when the patient has unusual aversions toward risk or certain outcomes, and when there is uncertainty and disagreement among physicians (10). The choice between surgery and radiation in Case 3.1 has many of these characteristics. In addition, participation in decisions might have other beneficial consequences for patients, such as increased sense of control, self-efficacy, and adherence to plans for care.

FULFILL LEGAL REQUIREMENTS

Physicians might consider informed consent "a nuisance, an alien imposition of the legal system that must be tolerated . . . but can be dealt with in relatively mechanical ways, such as making sure

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patients sign consent forms before major procedures (11).” Similarly, many patients are cynical about informed consent. In one study nearly 80% of patients said that the purpose of informed consent was to protect the physician (12).

REQUIREMENTS FOR INFORMED CONSENT

Ethically and legally, informed consent requires discussions of pertinent information, obtaining the patient’s agreement to the plan of care, and freedom from coercion (5).

INFORMATION TO DISCUSS WITH PATIENTS

Physicians need to discuss with patients information that is relevant to the decision at hand (Table 3-1). Most court decisions and legal commentaries use the term “disclose,” and, when summarizing legal doctrine, this book also uses this term. In general, however, we prefer the term “discuss” to emphasize that a dialogue between the physician and patient is preferable to a monologue by the physician.

Patients need to know the *nature* of the intervention, the expected *benefits*, the *risks*, and the likely *consequences*. In general, risks that are common knowledge, already known to the patient, of trivial impact, or very infrequent do not need to be discussed. For instance, patients do not need to be told about the nature of venipuncture, the rare risk of infection, or the minor discomfort of hematomas. On the other hand, for invasive interventions, courts have ruled that physicians need to discuss serious but rare risks, such as death or stroke. In Case 3.1, the physician should discuss with Mr. T the risks of surgical mortality, prolonged hospitalization, and long-term shortness of breath following surgery.

The risks of an intervention might include psychosocial as well as biomedical risks. For human immunodeficiency virus (HIV) and genetic testing, the pertinent risks are not the risks of venipuncture, but the risks of stigma and discrimination in employment or health insurance. Many states have enacted special provisions, requiring written informed consent and pretest counseling for HIV testing (13).

Patients also need to understand the *alternatives* to the proposed test or treatment and their risks, benefits, and consequences. In particular, the alternative of no intervention needs to be discussed. If a patient declines the recommended intervention, the physician needs to explain the adverse consequences of the refusal. In one case a court ruled that when a woman refuses a Pap smear, the physician needs to discuss how the test could diagnose cancer at an early stage and avert death through early treatment (14).

It is controversial whether physicians need to disclose information about themselves that affect patient outcomes (see Chapter 38). For example, patients might find it pertinent to know the *outcomes* of a surgical procedure at a given institution or by a particular surgeon, as contrasted to outcomes reported in the literature. Some states make such individualized outcome data for cardiac surgeons available to the public. In addition, the surgeon’s *experience* might be pertinent, because increased volume is associated with better outcomes for some operations and surgeons have a “learning curve” for new procedures. Another issue that patients might find pertinent is the *role of trainees* in their care, particularly with invasive or surgical procedures. As Chapter 36 discusses in detail, most patients want to know about the role of trainees and agree to their participation. The physician’s own health might also be pertinent to patient decisions. For instance, a patient might wish to seek a different provider if a physician is impaired because of alcoholism, dementia, or other medical conditions.

TABLE 3-1

Information to Discuss with Patients

- The nature of the test or treatment.
- The benefits, risks, and consequences of the intervention.
- The alternatives and their benefits, risks, and consequences.

Although some courts have ruled that physician-specific experience needs to be disclosed for some operations, other courts have not (15). If disclosure is guided by what a reasonable physician would disclose, disclosure of such information would not be legally required. However, from the ethical perspective of providing patients pertinent information to make informed decisions, such disclosure is desirable.

Physicians must take the initiative in discussing information rather than wait for patients to ask questions. Patients, who have far less medical knowledge than physicians, might not even know what questions to pose. Empirical studies show that physicians often fail to provide sufficient information for patients to make informed decisions (16).

The extent of the disclosure will depend on the clinical context. For conditions such as appendicitis or pneumonia, or if there is only one realistic option and it is highly effective, relatively safe, and strongly recommended, a detailed consent process might be of little benefit to patients (17).

It is controversial whether physicians need to inform patients of alternatives for care that they do not believe are medically indicated. Obviously, physicians do not need to mention treatments that have no scientific rationale, would provide no medical benefit, or are known to be ineffective or harmful, such as laetrile for cancer; nor do physicians need to discuss complementary or alternative medicines that they do not accept as valid. However, physicians should inform patients of alternatives that other reasonable physicians would recommend. Thus, a physician who believed that surgery was the best approach to Mr. T's lung cancer still ought to inform him about the option of radiation therapy.

Discussions about the proposed test or treatment and the alternatives should be conducted by the attending physician or by the physician performing the intervention, the proposed test or treatment, and the alternatives (18). Such discussions should not be delegated to nurses, medical students, or house officers. Some busy physicians who have already discussed an intervention with the patient during an office visit will ask a nurse or house officer to obtain the patient's signature on a consent form in the hospital. Although this approach is understandable because it saves time, it might be problematic if the patient has questions that an inexperienced physician or a nurse cannot answer.

PATIENT AGREEMENT WITH THE TREATMENT PLAN

Patients must agree with the intended plan of care. For major interventions, such as surgery, obtaining explicit written authorization is standard. Written consent signals the patient that the decision is important. In ambulatory care, oral agreement to the plan of care is usual because the risks are lower and because patients can choose to discontinue medications (19,20).

AGREEMENT SHOULD BE VOLUNTARY

Coercion and manipulation invalidate consent because they preclude free choices by patients. Coercion involves threats that are intended to control patients' behavior and that patients find irresistible (21). An example is a threat to discharge a patient from the hospital if he does not agree with the recommended care. Manipulation of information might also thwart informed decisions. For example, physicians might misrepresent the patient's condition or the nature of the proposed intervention. Coercion and manipulation contrast with persuasion, which is an attempt to convince the patient to act in a certain way by providing rational arguments and accurate data (21). Persuasion respects patient autonomy and, indeed, enhances it by improving the patient's understanding of the situation and the options.

Certain constraints on patients' choices are not coercive (4). The patient's prognosis might be so grim that all alternatives are undesirable and the patient has no "real choice." Warnings by the physician about the outcomes of choices or about the natural history of the illness are also not coercive because the physician makes no threat to bring about undesirable outcomes. Indeed, physicians would be remiss if they did not point out to patients the consequences of unwise choices.

Patients might lack the capacity to make informed decisions, as discussed in Chapter 10. For such patients, advance directives or appropriate surrogates should guide decisions (*see* Chapters 12 and 13).

OBJECTIVE

PATIENTS

Patients often lack information about their condition, only a physician can explain the complications of treatment, and patients often do not understand that they must give consent for treatment.

Physicians must take the time to explain the technical details of the treatment and the culture to read and understand the basic information.

PATIENTS

As shown in the case of Mr. T, physicians or family members must obtain consent and indicate the many do not know what a physician asks them to do. Patients often take medical decisions for themselves, most patients defer decisions to their physicians, but suggest that they should be more involved.

PATIENTS

A common problem is that some physicians intervene without the patient's consent, and some patients refuse to follow the physician's advice.

PATIENTS

Informed consent is often made impossible by the physician's failure to provide the patient with the information needed to make a decision. For example, a patient's decision is often driven by the physician's advice.

Although physicians give patients the information they need to make a decision, many patients do not understand the information.

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In some cases, patients do not make decisions for themselves, but defer decisions to their physicians.

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OBJECTIONS TO INFORMED CONSENT

PATIENTS DO NOT UNDERSTAND MEDICAL INFORMATION

Patients often do not recall information they have discussed with physicians, even basic information about the proposed treatment. In a study of cancer patients who had just consented to treatment, only 60% understood the purpose and nature of the treatment, 55% could name any complication, and 27% could name an alternative treatment. Furthermore, just 40% had read the consent form carefully (22). Many physicians have had similar experiences with patients and conclude that patients are unable to make decisions in an informed way.

Physicians, however, are partly to blame for patients' poor comprehension. Doctors often use technical jargon that is incomprehensible to laypeople. Informed consent forms are usually difficult to read and understand (23). More importantly, physicians often fail to provide patients with basic information about interventions (19,24,25).

PATIENTS DO NOT WANT TO MAKE DECISIONS

As shown in Case 3.1, some patients might not want to make decisions but instead defer to physicians or family members. This might be particularly true of patients from cultures where informed consent and autonomy are not as important as in the United States. Several older empirical studies indicate that although patients generally want information about their condition and treatment, many do not want to make decisions. In one study almost all hospitalized patients regarded the physician as the decision maker (24). Patients wanted information about plans for care in order to know what was going to happen and how to carry out those plans effectively. However, the only patients playing an active role in decision making were those with chronic diseases who needed to take medications regularly and to report changes in their condition. In ambulatory settings, although most patients want information about their illness, approximately one-half of the patients want to defer decisions to physicians (12,26). Many patients, however, want to play a more active role in decisions later, after they have experience with the prescribed medications (26). More recent studies suggest that about two-thirds of patients want to share decision making with physicians (27,28).

PATIENTS MAKE DECISIONS THAT CONTRADICT THEIR BEST INTERESTS

A common criticism of informed consent is that patients might make unwise or harmful choices. Some physicians fear that information about risks might cause patients to refuse medically beneficial interventions. Empirical studies, however, do not support these concerns. In one study of 104 refusals of inpatient treatment, none were attributed to disclosure of information (29). Fourteen patients, however, refused care because of inadequate information about tests or treatments.

PATIENTS OFTEN DECIDE WITHOUT DELIBERATING ABOUT RISKS AND BENEFITS

Informed consent assumes rational, deliberate patient decision making. However, patients might make important decisions without such deliberation. For example, people who donate a kidney or part of their liver for transplantation often decide to do so as soon as they learn of the opportunity. For example, donors might say that they had to do it or that they had no choice. Moreover, they commonly decide to donate before learning about the risks of the procedure. Instead, their decision is driven by a commitment to specific people and to helping others.

Although patients might not use all disclosed information, it is nonetheless important that physicians give patients pertinent information. Even if a patient decided to pursue a course of medical care upon first hearing about it, that patient may still reconsider upon learning more information.

PATIENTS MIGHT NOT WANT TO MAKE DECISIONS INDIVIDUALLY

In some cultures patients might be expected to involve their families in medical decisions rather than make decisions as individuals (5). In some cultures women might traditionally be expected to defer decisions to their husbands or fathers. Clearly, physicians need to allow patients to involve

others in their medical decisions if they choose to do so. However, physicians must avoid creating an expectation that patients must involve others in decisions, because not all patients from a given culture might agree with traditional decision-making practices.

LEGAL ASPECTS OF INFORMED CONSENT

Court rulings have shaped the doctrine of informed consent, with particular focus on what information must be disclosed to patients.

MALPRACTICE

Physicians who do not obtain informed consent might be found liable in civil suits for battery or negligence (5). *Battery* is the harmful or offensive touching of another person. Physicians might commit battery if they carry out surgery without the patient's consent or if the surgery exceeds the scope of patient consent (30). For instance, a physician might be liable for performing a mastectomy on a patient who had consented to only a biopsy, even if the intervention was medically appropriate, skillfully performed, and beneficial. This battery model, however, fits medicine poorly. Many cases do not involve physical touching of the patient, as when physicians prescribe drugs, fail to consider alternative approaches, or do not disclose information to the patient. In addition, battery requires that the physician intended to provide care without the patient's consent. Most cases of malpractice, however, involve unintentional actions.

The modern approach to malpractice, which has supplanted the battery model, is to hold physicians liable for *negligence*. To be found negligent, the physician must breach a duty to the patient, the patient must suffer a harm, and the breach of duty must cause the harm. With regard to informed consent, the patient needs to prove that the physician failed to disclose a risk that should have been disclosed, that the patient would not have consented had the risk been discussed, and that the risk occurred and caused harm. A crucial issue in malpractice law, therefore, is what risks should be discussed.

STANDARDS FOR DISCLOSURE

Full or complete disclosure of all information that physicians know about a particular condition is impossible. Thus, the issue is not *whether* physicians should limit the amount and types of information they discuss with patients, but rather *what* information should be discussed or omitted.

Courts have used several standards to determine what information to disclose to the patient (5). A slight majority of states have adopted a *professional standard*: The physician must disclose what a reasonable physician of ordinary skill would disclose in the same or similar circumstances. This is equivalent to providing the information that colleagues customarily provide. The professional standard has been criticized because patients generally want more information than physicians customarily discuss.

Many states have adopted a patient-oriented standard for disclosure: Physicians should disclose what a *reasonable patient* in the same or similar situations would find relevant to the medical decision. Generally, this standard requires more disclosure than the professional standard and is more consistent with the goal of promoting patient decision making and choices.

Some individuals, however, might desire more information than the standard "reasonable" patient. For example, a carpenter might be particularly concerned that a new medication might impair his or her dexterity or alertness. To accommodate individual patient needs fully, a few states have adopted a subjective standard for disclosure: The physician must provide information that the *individual patient* would find pertinent to the decision. This subjective standard for disclosure is problematic in malpractice litigation. If a rare, undisclosed complication occurs, the patient might claim that he would not have consented to the intervention if the physician had mentioned that particular risk. In hindsight, it might be difficult to decide whether this assertion is plausible.

In some states statutes specify that certain risks need to be disclosed—for example, "brain damage" or "loss of function of any organ or limb (5)." State courts have also ruled on issues of disclosure. A California court ruled that a physician did not have to give a quantitative estimate of life expectancy to a patient with pancreatic cancer. His widow claimed that if he had known such information, he would have declined chemotherapy and arranged his business affairs (31).

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CONSENT FORMS

The consent form documents that the patient agreed to treatment. In some states a signed consent form provides a legal presumption of valid consent (32). However, a signed consent form is not tantamount to informed consent because the discussion of the risks, benefits, alternatives, and consequences might be inadequate (5).

EXCEPTIONS TO INFORMED CONSENT

Several exceptions to informed consent illustrate how acting in the patient's best interests might supersede patient self-determination. These exceptions need to be carefully limited so that they do not undermine informed consent.

LACK OF DECISION-MAKING CAPACITY

When patients lack decision-making capacity, an appropriate surrogate should give consent or refusal, following the patient's previously stated preferences or his or her best interests (*see* Chapter 4).

EMERGENCIES

In an emergency, delaying treatment to obtain informed consent might jeopardize the patient's health or life. Legally, the courts have recognized a doctrine of *implied consent*: Because reasonable persons would consent to treatment in such emergency circumstances, physicians may presume that the patient in question also would consent. Few people would object to treating life-threatening emergencies, such as an impending airway obstruction in anaphylaxis, without the patient's explicit consent. It is often possible to abbreviate the process of disclosure and consent in an urgent situation, rather than dispense with it altogether. In addition, the process of informed consent can often be initiated while the treatment is being started.

The emergency exception should not be used when informed consent is feasible or if it is known that a particular patient does not want the treatment. For example, terminally ill patients might have indicated that they do not want cardiopulmonary resuscitation (CPR). If such patients seek emergency care, the usual presumption that CPR should be initiated in case of cardiac arrest would not be valid.

Some physicians claim that consent is implied when a patient seeks care from a hospital or signs a general consent form upon admission. The implication is that informed consent for specific tests or treatments is unnecessary. However, this use of "implied consent" is unacceptable, because it allows physicians to administer any type of care they choose. When patients come to a hospital, they do not give physicians *carte blanche*. Most patients would probably agree to certain interventions, such as diagnostic testing, but would want to base further decisions on new information.

THERAPEUTIC PRIVILEGE

Physicians may withhold information when disclosure would severely harm the patient or undermine informed decision making by the patient (1). For example, a patient might be depressed and have a history of previous suicide attempts in response to serious medical diagnoses. Telling such a patient he has cancer might provoke another suicide attempt. However, the concept of therapeutic privilege needs to be sharply circumscribed. The likelihood that the patient will feel sad does not justify withholding a serious diagnosis. Therapeutic privilege also does not allow the physician to "remain silent simply because divulgence might prompt the patient to forego therapy the physician feels the patient really needs (33)."

WAIVER

Patients like Mr. T in Case 3.1 might not want to participate in making decisions about their care. Ethically and legally, patients' requests to waive the right of informed consent should be respected. Self-determination would be undermined if patients were forced to participate in decision making

against their wishes. Shared decision making entitles patients to participate actively in health care decisions but does not require them to do so (4). To be ethically valid, a waiver of informed consent must itself be informed. Patients must appreciate that they have the right to receive information and to make decisions about their care. Physicians can give patients the option to not receive information or make a decision without thereby suggesting that they should do so. Physicians must keep in mind that patients might later want to participate more actively in decisions.

PROMOTING SHARED DECISION MAKING

The process of shared decision making generally requires multiple discussions between the physician and patient (Table 3-2) (34).

ENCOURAGE THE PATIENT TO PLAY AN ACTIVE ROLE IN MAKING DECISIONS

Physicians can encourage patient involvement in decisions, even with patients like Mr. T in Case 3.1 who defer to their judgment. Mr. T's doctor might say, "I'd be glad to tell you what I think is best for you. But first I need to understand what is important to you."

Elicit the Patient's Perspective about the Illness

Physicians can elicit the patient's concerns, expectations, and values regarding medical care through open-ended questions. When Mr. T's physician asked him what was most important to him over the next few years, Mr. T replied that he wanted to continue to care for his sister, who had stomach cancer. Another useful question is "What concerns you the most about your health?"

Build a Partnership with the Patient

Physicians can acknowledge that the decision is complex and difficult (34). Moreover, doctors can affirm their dedication to working for the patient's well-being: "We'll work together to make the best decisions for you."

ENSURE THAT PATIENTS ARE INFORMED

Provide Comprehensible Information

To enhance patient understanding, physicians should use simple language and avoid medical jargon. Innovative ways of presenting information include videotapes, interactive videodiscs, and discussions with patients who have had the intervention (34,35).

TABLE 3-2

Promoting Shared Decision Making

- Encourage the patient to play an active role in decisions.
 - Elicit the patient's perspective about the illness.
 - Build a partnership with the patient.
- Ensure that patients are informed.
 - Provide comprehensible information.
 - Try to frame issues without bias.
 - Interpret the alternatives in light of the patient's goals.
 - Check that patients have understood information.
- Protect the patient's best interests.
 - Help the patient deliberate.
 - Make a recommendation.
 - Try to persuade patients.

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Try to Frame Issues without Bias

People are more likely to accept a treatment if the outcomes are phrased in terms of survival, rather than in terms of death (36). Lung cancer patients are more likely to prefer surgery to radiation therapy if outcomes are framed as the probability of living rather than the probability of dying (36). Moreover, surgery is more attractive when survival data are presented as the average number of years lived rather than as the probability of surviving a given time period. To minimize bias, Mr. T's physician should describe the likelihood of both surviving and dying after surgery and radiation therapy.

Physicians also need to consider how to frame the disclosure of rare but serious risks, such as the risk of an anaphylactic reaction to radiographic contrast material (37). Patients might infer incorrectly that a risk is significant because the physician has mentioned it. Physicians should put the risk in context, for example, by saying, "I believe that this is a very small risk, compared with the information we would gain from the test."

Interpret the Alternatives in Light of the Patient's Goals

In some clinical situations alternative courses of care have strikingly different benefits and burdens for the patient. Examples include surgery, hormonal treatment, or watchful waiting for benign prostatic hypertrophy and lumpectomy plus radiation or mastectomy for localized breast cancer. In these situations, which have been called *toss-ups*, the patient's goals and values are decisive. In Case 3.1, Mr. T's physician explained that he would be unable to care for his sister while recuperating from surgery and also that he might die from the operation.

Check That Patients Have Understood Information

Disclosure by the physician is not equivalent to comprehension by the patient. It is helpful to ask patients to repeat the information in their own words.

PROMOTE THE PATIENT'S BEST INTERESTS

The guideline of beneficence requires physicians to help patients make decisions that are in their best interests (*see* Chapter 4). In addition to providing information, physicians should help patients deliberate about their choices.

Help Patients Deliberate

Patients often clarify their values and preferences only in the context of an actual decision, rather than having firm preexisting values that they apply to the decision. Thus, patients commonly need to spend time deciding what option they prefer. In some situations the decision is a close call; the balance of benefits and risks of the various options are not far apart. Sometimes patients need to compare a risky treatment that promises benefit against foregoing the treatment and accepting the risk of a complication as part of the natural history of the disease. For example, in deciding whether to start anticoagulation for atrial fibrillation, patients differ in how they balance the risk of serious bleeding against the risk of an embolic complication (38,39). The physician can help the patient frame such decisions by asking whether the patient is the kind of person who wants to try everything to prevent a complication or the kind of person who would rather suffer the natural course of illness rather than the adverse effects of interventions.

Make a Recommendation

Physicians should not merely list the alternatives and leave it up to the patient to decide (40-42). Patients commonly seek a recommendation regarding what plan is most likely to fulfill their goals. Physicians should offer a recommendation on the basis of the patient's values. In light of Mr. T's desire to care for his sister, his doctor recommended radiation therapy.

Try to Persuade Patients

Physicians should also try to dissuade patients from choices that are clearly contrary to their best interests, as judged by their own values (2).

In summary, shared decision making respects patient self-determination. In order for patients to make informed choices, physicians must discuss with them the alternatives for care and the

benefits, risks, and consequences of each alternative. Physicians also need to encourage patients to play an active role in decision making and to ensure that patients are informed.

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Promoting the Patient's Best Interests

Patients may reject the recommendations of their physicians, refusing beneficial interventions or insisting on interventions that are not indicated. In such cases physicians are torn between respecting patient autonomy and acting in the patients' best interests. If physicians simply accept unwise patient decisions in the name of respecting patient autonomy, their role seems morally constricted. This chapter discusses how physicians can protect the well-being of patients while avoiding the pitfalls of paternalism.

PATIENT REFUSAL OF BENEFICIAL INTERVENTIONS

The following case illustrates how patients may refuse beneficial interventions.

CASE 4.1 Refusal of surgery for critical aortic stenosis.

Mrs. N is a 76-year-old widow with aortic stenosis. For several years she has been refusing further evaluation, saying that she would not want surgery. After an episode of near-syncope, she agrees to echocardiography, mostly to humor her physician. Critical aortic outflow obstruction is found. Her primary care physician strongly recommends valve replacement. The risks of surgery are unacceptable to her, particularly the risk of prolonged hospitalization or neurologic or cognitive impairment. Having lived a full life, she says she welcomes a sudden death rather than a prolonged decline. In the past she has been reluctant to visit physicians, undergo tests, or take medications. She leads an active life, writing a resource book for senior citizens, leading several volunteer organizations, and enjoying concerts.

Mrs. N's physicians believe that her refusal conflicts with her best interests. With valve replacement she is likely to live longer and avoid debilitating symptoms such as chest pain and dyspnea. Refusal of surgery might result in what she fears most: progressive decline and loss of independence.

How can physicians respond to Mrs. N's refusal? On the one hand, it would be disrespectful and impractical to override her refusal and operate without her consent. On the other hand, accepting her refusal without further discussion might result in an adverse outcome that could have been averted. What attempts by physicians to persuade Mrs. N to agree to surgery are warranted? To address these issues, physicians need to understand the ethical guidelines of doing no harm and acting in their patients' best interests.

DOING NO HARM TO PATIENTS

The ethical guideline of nonmaleficence requires people to refrain from inflicting harm on others. Prohibiting harmful actions is the core of morality (1). For instance, the Ten Commandments prohibit killing, lying, and stealing. Avoiding harm is generally considered a more stringent ethical obligation than providing benefit (1).

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CHAPTER 4

The widely quoted maxim "Do no harm" has several distinct meanings (2,3). First, physicians should not provide interventions that are known to be ineffective. Second, physicians should not act maliciously, as by providing substandard care because they dislike the patient's ethnic background or political views. Third, doctors should also act with due care and diligence. Fourth, the maxim sometimes is cited as "Above all, do no harm," or, more impressively in Latin, *Primum non nocere*. If physicians cannot benefit patients, they should at least not harm them or make the situation worse. Fifth, when benefits and burdens are evenly balanced, physicians should err on the side of not intervening.

However, the precept "do no harm" provides only limited guidance. Many medical interventions, such as the aortic valve replacement mentioned in Case 4.1, offer both great benefits and serious risks and side effects. Doing no harm would literally preclude such interventions, yet some patients may accept substantial risks to gain medical benefits (4). Furthermore, as we discuss next, merely doing no harm seems a limited view of the physician's role (5).

PROMOTING THE PATIENT'S BEST INTERESTS

The ethical guideline of beneficence requires physicians to promote patients' "important and legitimate interests (5)." This guideline arises from the nature of the doctor-patient relationship and of medical professionalism.

THE FIDUCIARY NATURE OF THE DOCTOR-PATIENT RELATIONSHIP

Physicians have special responsibilities to act for the well-being of patients because patients are often impaired in significant ways by their illness (6,7). Furthermore, the stakes are high; poor decisions might place patients' health or lives at risk.

Reasons for the Fiduciary Relationship

Patients are vulnerable. Because illness might undermine patients' independence and judgment, people might be less able to look after their own interests when they are sick. Because of this vulnerability, patients often depend on physicians for advice and trust their recommendations.

Physicians have expertise that patients lack. Physicians have expert knowledge as well as the experience and judgment to apply it to the patient's individual circumstances.

Patients rely on their physicians. It is often difficult for patients to obtain information and advice other than through physicians. Often, they have no previous experience in making medical decisions. In serious illness, patients might have little time to seek second opinions. Similarly, it is hard for laypeople to determine whether a physician's advice is sound or to evaluate a physician's skills. Hence, patients rely on the advice of their physicians.

Definition of a Fiduciary Relationship

Legally, relationships between professionals and clients are characterized as fiduciary. The term fiduciary is derived from the Latin word *fidere*, to trust. Fiduciaries hold something in trust for another. They must act in the best interests of their patients or client, subordinating their self-interest. Fiduciaries are held to higher standards than ordinary citizens and businesspeople, who use their knowledge and skill for their own self-interest, rather than for the benefit of their customers (7). Ordinary business relationships are characterized by the phrase *caveat emptor*, "let the buyer beware," not by trust and reliance.

Many arrangements in managed care challenge the fiduciary nature of the doctor-patient relationship (see Chapter 34). Financial incentives under managed care encourage physicians to act in their own self-interest or in the interest of third parties such as hospitals, physician groups, or managed care plans, rather than in the best interests of patients. Utilization review and practice guidelines might limit physicians' freedom to act on behalf of their patients. Patients might fear that physicians no longer exercise independent clinical judgment but simply carry out bureaucratic policies set by administrators.

THE NATURE OF PROFESSIONALISM

In professional codes of ethics, physicians promise to serve the best interests of patients. Literally, physicians "profess" to use their skills to heal and comfort the sick, encouraging patients to rely on them and promising to act in a fiduciary manner (8). In return for physicians acting for the good of their patients, society grants physicians a great deal of autonomy in selecting applicants for medical schools and postgraduate training, in establishing standards for certification, and in disciplining practitioners (9).

PROBLEMS WITH BEST INTERESTS

The idea that physicians should act in the best interests of patients is indisputable. However, in any given case the actions that are in the patient's best interests might be controversial.

DISAGREEMENTS OVER WHAT IS BEST FOR A PATIENT

People may disagree over the goals of care or the assessment of the benefits and burdens of an intervention. In Case 4.1, the physicians' goal is to increase the patient's likelihood of survival. However, the patient's goal is to avoid physical and mental decline, particularly in the perioperative period. Furthermore, the physicians and patients may weigh the risks and benefits of surgery differently (10). Physicians tend to focus on the prospect of long-term survival, while Mrs. N is more concerned about the short-term risks of surgery and her quality of life (11).

QUALITY OF LIFE

The term *quality of life* is used in many ways. Factors that might be considered include:

- The symptoms of the illness and the side effects of treatment
- The patient's functional ability to perform basic activities of living such as walking, shopping, and preparing meals
- The patient's experiences of happiness, pleasure, pain, and suffering
- The patient's independence, privacy, and dignity

Competent patients usually consider their quality of life as well as the duration of life when making health care decisions. In some situations a patient with a serious illness may decide that her quality of life is so poor that interventions are unacceptably burdensome. The principle of autonomy requires respecting a patient's judgments about quality of life when that patient is competent and informed. More controversy exists if other persons are making the judgments.

Quality of Life Judgments by Others Might Be Problematic

Persons with chronic illness such as coronary artery disease and chronic obstructive lung disease rate their quality of life higher than their physicians do (12). Similarly, elderly patients who have survived a hospitalization in the intensive care unit (ICU) view their quality of life higher than their family members do (13). Such discrepancies are not surprising. Many patients learn to cope with chronic illness over time, develop support systems, and continue to find substantial pleasure in life. Furthermore, quality of life might improve substantially if in-home assistance or adaptive devices are provided. In addition, assessments of quality of life might be discriminatory if they are based on the patient's economic value to society or social worth. These considerations are not pertinent to medical decisions, which should be based on need and likely benefit (14). Thus, quality of life judgments by others might be inaccurate and biased unless they reflect the patient's own assessment of quality of life.

Quality of Life in Patients with Severe Neurologic Impairment

Consider a patient with severe Alzheimer disease who cannot respond to questions. He usually appears comfortable and smiles when music is played or when someone gives him a back rub. However, he has catastrophic reactions, shouting and striking people when asked to take a bath.

Some writers argue that a patient's quality of life falls below a minimal acceptable level if he lacks qualities that are considered essential to being a person (15,16). In this view patients in a persistent

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vegetative state or who cannot survive outside an ICU have an unacceptable quality of life. These authors contend that such lives are "useless" and "not worth living and that it is not a goal of medicine to sustain biological existence in such situations (15)."

Others reject such quality of life considerations. Some fear that such considerations will lead to discrimination against people with disabilities. Proponents of a "right to life" believe that biologic life should be prolonged, regardless of prognosis or quality of life. This position is often based on fundamentalist religious beliefs about the sacredness of life. These disagreements illustrate how determinations of quality of life by others might be problematic unless they are based on the patient's own judgments.

MEDICAL PATERNALISM

Historically, beneficence rather than respect for persons was the dominant ethical principle for physicians. Doctors made decisions for the patient on the basis of what they believed was the patient's best interest. This approach to decision making has been termed *medical paternalism* (17), analogous to how parents make decisions for their children. Deferring to the physician's recommendations is reasonable in many acute illnesses or emergencies: when cure is possible, when the benefits of therapy far outweigh the risks, and when treatment must be started promptly.

Definition of Paternalism

Philosophers define paternalism as intentionally overriding a person's known preferences or actions in order to benefit that person (17). They further distinguish two types of paternalism. In weak or soft paternalism, the patient's decisions are not informed or are not voluntary (17). If a patient's autonomy is impaired or in doubt, it is appropriate for physicians to intervene, at least temporarily. The justification is that patients should be protected from harming themselves through nonautonomous decisions and actions. Intervening to determine whether a patient is competent and informed is a minimal imposition on patient autonomy, compared to the possible harms of allowing an incompetent patient to act unwisely.

In strong or hard paternalism, a patient's autonomous choices are overridden. An example is withholding a diagnosis or a test result requested by a patient because the physician believes the information will greatly upset the patient. When writing about paternalism, philosophers generally mean strong or hard paternalism (17). Strong or hard paternalism has been sharply criticized, as we will discuss in the next section.

Problems with Medical Paternalism

Critics of (strong) paternalism raise several objections (17). First, value judgments are unavoidable in clinical medicine, and patients, not physicians, should make them. Physicians can define the burdens and benefits of an intervention, but only Mrs. N can decide whether the surgical risk and side effects are worth the chance for long-term survival and relief of symptoms.

Second, the belief that patients cannot make wise medical decisions is a self-fulfilling prophecy. If patients are not informed, they will not be able to make meaningful choices. Similarly, patients who sense that they have no decision-making power will become passive. In contrast, if patients are empowered to make decisions, they generally ask questions, seek information, and take responsibility for difficult choices.

Third, physicians might seek to override a patient's wishes because of their own psychological and emotional reactions to the case. Some physicians are affronted if patients reject their recommendations. "Refusal of treatment is seen by physicians as a rejection of an offer of help, which in turn may be seen as a rejection of the person making the offer. As a result, physicians may feel angry, frustrated, and unwilling to explore the underlying basis of refusal (18)."

PATIENT REQUESTS FOR INTERVENTIONS

Patients sometimes insist on medical interventions that physicians consider far more harmful than beneficial. Such insistence might frustrate and anger physicians. Disagreements over patient requests are often framed as conflicting rights: The patient claims the right to decide about his

medical care while the physician asserts a countervailing right to follow her professional judgment. Framing the issues in this way, however, generally leads to stalemate. A more fruitful approach is to examine the benefits and burdens for the patient.

INTERVENTIONS OUTSIDE APPROPRIATE MEDICAL PRACTICE

CASE 4.2 Request to monitor side effects of a performance-enhancing drug.

A 22-year-old college swimmer is taking oral anabolic steroids, which she obtains through friends at the gym where she lifts weights. She is aware of the long-term side effects but plans to use the drugs only for the next year while she is competing. Many of her competitors are using steroids, and she cannot remain competitive unless she takes them also. She asks her physician to monitor her for side effects but not to prescribe the drugs.

In this case the patient is using drugs for enhancement, not for the treatment or prevention of illness. Many physicians believe that enhancement of normal function is not an appropriate goal of medicine. In this case the medical risks might be serious. There are additional reasons that the physician might decline this request. Using performance-enhancing drugs is unfair to other competitors and violates rules governing athletic competitions. Even though this patient is not asking the physician to prescribe the steroids, the physician might believe that monitoring for side effects condones the practice.

From another perspective, however, the physician can frame the request as preventing harm to the patient. Patients commonly use other substances that might harm their health, such as cigarettes and alcohol, which they obtain without prescription. However, physicians continue to follow patients using such substances, monitor them for adverse effects, and treat complications, while still urging them to stop. Indeed, by maintaining a supportive doctor-patient relationship, physicians might be better positioned to persuade patients to stop taking harmful substances.

INTERVENTIONS WHOSE BENEFIT CAN ONLY BE ASSESSED BY THE PATIENT

CASE 4.3 Request for controlled drug for pain.

A 56-year-old man has been disabled by chronic back pain for 10 years. Extensive evaluations, including a magnetic resonance (MR) scan, have been negative. Exercises and physical therapy have provided only minor improvement. After changing health insurance plans, the patient visits a new physician and requests a refill of a prescription for eight 160-mg tablets of oxycodone (Oxycontin) daily. He says that he has not changed the dosage in several years. His new physician does not prescribe opioids at this strength and dosage for chronic pain. She wants to wean the patient off opioids and to help him live an active life despite the pain. The patient refuses a referral to a pain clinic. "I know that Oxycontin works. Nothing else helps me."

In this case the risks of treatment are significant. Oxycodone has been abused, diverted to illegal sales, and implicated in local outbreaks of opioid abuse. Because only patients can assess the severity of pain, some physicians are uncomfortable prescribing opioids, particularly when the dosage seems high. In this case only the patient can assess the effects of treatment. Physicians might be uncomfortable adjusting the dosage of drugs on the basis of only the subjective report of the patient without objective signs or tests.

The benefits to the patient are also significant. Pain is undertreated by physicians and causes substantial suffering. Many experts in pain management believe that the regular use of opioids for chronic pain syndromes rarely leads to addiction and is effective in relieving pain and enhancing function (19). The fact that pain can only be assessed through the patient's self-report should not lead physicians to downplay the importance of treating it effectively.

The ethical guideline of respecting patient autonomy and the legal doctrine of informed consent give patients the *negative* right to refuse unwanted treatments (see Chapter 3). However, this patient claims the *positive* right to receive a specific drug. Some countries allow patients to buy many drugs, including antibiotics, without a physician's prescription. In the United States, however, only physicians are licensed to order tests or prescribe medications. Prescriptions for opioids such as oxycodone require special physician registration numbers from the Drug Enforcement Agency and, in some states, special triplicate prescription forms. These restrictions address the

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concern that opioids might be diverted to illegal uses or used to maintain an addiction. In California a physician may prescribe opioids and other controlled substances only if "in good faith he believes" that the patient's medical condition requires it (20).

INTERVENTION WITH SMALL BENEFIT BUT NO RISKS

CASE 4.4 Request for an expensive, low-yield test.

A 41-year-old bus driver has episodes of crampy abdominal pain and alternating diarrhea and constipation. One year ago, after an evaluation that included colonoscopy, she was diagnosed with irritable bowel syndrome (IBS). Dietary manipulations have been ineffective. On the advice of a friend, she asks her doctor to order an abdominal computed tomography (CT) scan because when the cramps are severe she fears something serious has been missed. She also says that "if doctors could only find out what is causing this, they would be able to do something about it." She refuses to discuss psychosocial issues about her illness or to try antidepressants that inhibit serotonin reuptake, saying that "my problems aren't in my head."

The physician's goal in Case 4.4 is to help the patient cope with a chronic medical condition and live an active life despite her symptoms. However, the patient's goals are relief of her symptoms and reassurance that her condition is not dangerous. Because of their divergent goals for care, it is understandable that the patient and physician disagree on weighing the benefits and burdens of the CT scan.

To the patient in Case 4.4, a scan has little medical risk and potentially great benefit. She believes that a negative scan would provide reassurance. In the unlikely event that the scan is abnormal, her course of care would be dramatically changed. In contrast, from the physician's perspective, a negative scan result is unlikely to lead to reassurance. Patients who seek "just another test" for reassurance often request further tests in a fruitless quest for a definitive diagnosis. Articles on IBS advise against additional diagnostic tests if a thorough initial work-up is negative and the clinical course is typical (21,22). In other situations the medical risks of the requested therapy might be serious. If the patient in Case 4.4 had requested exploratory surgery for reassurance or to establish a definitive diagnosis, the physicians should certainly have demurred.

ALLOCATING RESOURCES FAIRLY

Given the soaring cost of health care, physicians have a duty to allocate health care resources fairly and cannot ignore the costs of patient requests. Expensive high-technology procedures such as the CT scans noted in Case 4.4 drive up the cost of medical care. In addition, CT scans might reveal lesions that require further costly evaluation but ultimately prove to be clinically insignificant.

Cost, however, should not be the main reason for refusing patient requests. Under the current health care system, physicians have no explicit societal mandate to limit care in order to control costs. In managed care systems potential conflicts of interest make it problematic to limit highly beneficial care on the basis of cost (see Chapter 32).

The primary consideration should be the benefits and risks to the patient, rather than costs. If the intervention's medical risks outweigh any benefits for the patient, the patient's request can be refused without reference to costs. Patients who have financial incentives to control costs—through substantial copayments—are less likely to request such interventions. Thus, when patients and physicians both have financial incentives for cost-effective medicine, situations like Case 4.4 might be easier to resolve.

Cost might determine how much time and effort physicians should spend on trying to dissuade the patient. The physician should spend more time trying to discourage an expensive CT scan than in discouraging inexpensive tests. If the patient with IBS in Case 4.4 wanted a simple blood test that offered little benefit, few physicians would strongly object.

REACHING AGREEMENT ON BEST INTERESTS

Through continued discussions with patients, physicians can promote the best interests of patients while recognizing patients' ultimate power to decide (Table 4-1). Chapter 14 gives detailed recommendations for such discussions.

TABLE 4-1

Promoting the Patient's Best Interests

Understand the patient's perspective.

Address misunderstandings and concerns.

Try to persuade the patient.

Negotiate a mutually acceptable plan of care.

Ultimately let the patient decide.

Physicians should recommend what they believe is best for the patient from the perspective of the patient's values and preferences. In shared decision making, physicians should not merely present patients with a list of alternatives and leave them to decide.

Physicians should try to dissuade patients from unwise decisions. Persuasion respects patients and fosters their autonomy. Persuasion might include talking to the patient on several occasions and asking the patient to talk to family members, friends, other physicians, or other patients who have had the intervention. Persuasion needs to be distinguished from deception and threats. The latter are wrong because they undermine the patient's autonomy. Persuasion must also be distinguished from badgering the patient. Continual attempts to convince patients to change their minds might be counterproductive. It might be better to acknowledge that the choices are difficult, allow patients more time to decide, and give them more control over the decision-making process.

In summary, physicians need to respect patient autonomy and act in the patient's best interests simultaneously. Physicians have a fiduciary obligation to act for the well-being of patients as patients would define it. Physicians can satisfy the ethical guidelines of beneficence and autonomy by understanding the patient's perspective, by trying to persuade patients, and by negotiating a mutually acceptable plan.

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Confidentiality

Patients reveal to physicians sensitive personal information about their medical and emotional problems, their alcohol and drug use, and their sexual activities. The presumption is that physicians should maintain confidentiality of patient information. However, exceptions to confidentiality might be warranted to prevent serious harm to third parties or to the patient (Table 5-1). The human immunodeficiency virus (HIV) epidemic, the development of computerized medical records, and the explosion of genetic information have sharpened controversies over confidentiality. In 2003 the federal government issued health privacy regulations, also known as HIPAA *regulations*, because the 1996 Health Insurance Portability and Accountability Act mandated them.

THE IMPORTANCE OF CONFIDENTIALITY IN MEDICINE

REASONS FOR CONFIDENTIALITY

Keeping medical information confidential shows respect for patients (1,2). Patients want to control access to sensitive personal information and expect physicians to maintain confidentiality. Maintaining confidentiality also has beneficial consequences for patients and for the doctor-patient relationship. It encourages people to seek medical care and discuss candidly sensitive issues, such as psychiatric illness, sexually transmitted diseases, and substance abuse. In turn, treatment for these conditions benefits both the individual patient and public health. Furthermore, confidentiality prevents harmful consequences to patients, such as stigmatization and discrimination. Patients might fear that employers will gain access to their health information and discriminate against them.

Respect for confidentiality is a strong tradition in medicine. The Hippocratic Oath enjoins physicians, "What I may see or hear in the course of the treatment...which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about (3)." Modern professional codes similarly urge physicians to maintain confidentiality. The legal system may also hold physicians liable for unwarranted disclosure of medical information (4).

DIFFICULTIES MAINTAINING CONFIDENTIALITY

Maintaining confidentiality is increasingly difficult in modern medicine. Many people have access to medical records, including the attending physician, house staff, students, consultants, nurses, social workers, pharmacists, billing staff, medical records personnel, insurance company employees, and quality-of-care reviewers (5). Computerized medical records, which improve access to medical information, also allow more serious breaches of confidentiality. Confidentiality can be violated at any computer station, extensive data on each patient is available, and information on a large number of patients can be accessed at once (6). Fax and e-mail also present opportunities for confidentiality to be broken (7).

TABLE

Exceptions

Exceptions to Reporting Infectious Diseases
 Injuries caused by Partner not
 Warnings to Violence by Infectious
 Exceptions to Child abuse
 Elder abuse
 Domestic violence

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TABLE 5-1

Exceptions to Confidentiality

Exceptions to protect third parties

- Reporting to public officials
- Infectious diseases
- Impaired drivers
- Injuries caused by weapons or crimes
- Partner notification by public health officials
- Warnings by physicians to persons at risk
- Violence by psychiatric patients
- Infectious diseases

Exceptions to protect patients

- Child abuse
- Elder abuse
- Domestic violence

Many breaches of confidentiality, however, result from health-care workers' indiscretions. Caregivers might discuss patients by name at parties or even in hospital elevators or cafeterias (8,9). Although many physicians take such discussions for granted, patients object to such breaches of confidentiality (8). As a court ruling asked pointedly, "What policy would be served by according the physician the right to gossip about a patient's health (4)?"

WAIVERS OF CONFIDENTIALITY

Patients commonly give physicians permission to disclose information about their condition, for example, to other physicians or to insurance companies. Patients might not appreciate that signing a general release allows the insurance company to further disseminate the information. Insurance companies generally place patients' diagnoses in a computerized database that is accessible to other insurance companies or to employers without further permission from the patient (10).

COUNTERVAILING ETHICAL GUIDELINES

Although confidentiality is important, it is not an absolute value. In some situations, overriding confidentiality might be justified in order to provide important benefits to patients or to prevent serious harm to third parties. Access to information might be needed to provide high-quality medical care to patients or to protect the public health. These exceptions require careful justification, because not every instance of benefit to patients or prevention of harm to others warrants overriding confidentiality.

FEDERAL HEALTH PRIVACY REGULATIONS

Under the HIPAA health policy regulations, health care providers are required to set policies and procedures about privacy, educate staff, and provide patients with notice about their privacy rights and how the organization uses and discloses personal health information (PHI) (11). Providers are permitted to use and disclose PHI without patient authorization for treatment, payment, and health care operations. Health care operations include training programs, quality improvement, and accreditation and licensing. Providers may disclose information as required by public health laws and regulations. Patients must give specific authorization to disclose psychotherapy notes. Specific patient authorization is required to use PHI for research and marketing, although important exceptions are permitted.

Providers are required to use the minimum PHI necessary to achieve these desired purposes. For patient care, the full medical record may be accessed. Providers must also take reasonable

safeguards against prohibited or incidental use or disclosure of PHI. Patients are permitted to examine and copy their records, to request amendments to their records, to request to receive information by alternative means and locations (such as not leaving messages on an answering machine), and to obtain a list of disclosures of their information. Because the regulations set criminal penalties for intentional violations, many risk managers are interpreting the regulations conservatively. These federal regulations establish a minimum level of protection; state laws and organizational policies might be stricter.

Good patient care requires communication among various health care providers. In the course of care, incidental disclosure of information and breaches of confidentiality might occur. Physicians should take reasonable precautions to prevent inappropriate disclosures but should not forego communications that might be essential in patient care (11). For example, physicians might communicate with other providers by e-mail or fax without explicit patient authorization, but should take such precautions as keeping fax machines in areas where other patients cannot access them. Furthermore, physicians can discuss patients at the nursing station, provided that they keep their voices down and pause when someone or a patient or visitor approaches.

DISCLOSING THE PATIENT'S CONDITION TO OTHERS

Disclosure of patient information to family members, friends, or the press might raise ethical issues.

DISCLOSURE TO RELATIVES AND FRIENDS

Relatives and friends often ask about the patient's condition. Most patients want the physician to talk to their family, and usually physicians do not even ask the patient's permission to do so. In some cases, however, the patient might not want the information disclosed.

CASE 5.1 Estrangement from relatives.

A 32-year-old woman is admitted to the hospital after a serious automobile accident. She is disoriented and confused. The patient's sister requests that the patient's husband not be given any information. The patient has previously told the physician about her hostile divorce proceedings. The husband, however, learns that she is hospitalized and inquires about her condition.

The HIPAA privacy regulations establish a reasonable approach to this issue. Health care providers need to notify patients that relatives will be informed unless the patient requests that they not be. In ethical terms, the physician can presume that patients would want their relatives notified. In Case 5.1 the physician can conclude that this presumption no longer holds. Thus, the physician may give only minimal information to the husband in order to allay his fears about her condition but refer him to the patient's sister or other relatives for details. Similarly, physicians can provide information about a patient's condition and treatment to family members and other people involved in the patient's care, provided that the patient does not object. Often, such communication is needed to help monitor the patient, arrange follow-up care, or ensure that medications are taken as prescribed.

INFORMATION ABOUT PUBLIC FIGURES

The press might seek information about patients who are public figures or celebrities. The public and the news media might have legitimate reasons to know medical information about a public figure. For instance, a political candidate's health is an important concern to voters (12) yet famous people have a right to confidentiality, as do all people. The physician and hospital should ask the patient or appropriate surrogate what information, if any, should be released.

OMITTING SENSITIVE INFORMATION FROM MEDICAL RECORDS

Patients who are concerned about breaches of confidentiality may ask physicians to omit sensitive information from their medical records.

Confidentiality

CASE 5.2 Omission

A nurse who is in a physician's office knows that many of his patients have a psychiatric history. If he has no symptoms,

Physicians might mismanage the quality of care. In addition, documenting insurance payment information from medical records might be inferred.

The purpose of confidentiality is to protect the patient's privacy. The patient is of confidentiality of medical records. The medical record should be kept separate from other notes.

OVERRIDING

Overriding patient confidentiality illustrates. HIPAA is overridden by state law.

CASE 5.3 Risk of

A 32-year-old accident victim is undergoing anonymous testing. The patient is concerned about the results of the testing and that she can be tested without her consent. The physician notifies the wife.

The ethical guidelines require the physician to notify other people and to notify persons who are expected, as in the case of a partner. In addition, physicians have a duty to notify partners who are in some circumstances.

JUSTIFICATION

The balance between the patient's right to privacy and society through state policy allows all physicians in their offices to have exceptions to confidentiality.

- The potential harm to the patient
 - The likelihood of harm
 - There is no less effective way to protect the patient
 - Breaching confidentiality
 - Harm to the patient
- Disclosure should be made to persons with a need to know.

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CASE 5.2 Omission of information from the medical record.

A nurse who is in excellent health has a routine checkup at the hospital where he works. He asks his physician not to write in the medical record that he had been severely depressed several years ago. He knows that many people in the hospital might see his record, and he does not want colleagues to know his psychiatric history. He also fears that he will have difficulty changing jobs if his history is known, even if he has no symptoms at the time.

Physicians might fear that omitting medical information from patient records might compromise the quality of care. Important clinical information might not be available in an emergency. In addition, documentation of the patient's current condition and treatment might be required for insurance payment or authorization for services. Furthermore, it might not be feasible to exclude information from an electronic medical record. Even if a diagnosis is omitted from the record, it might be inferred from the patient's laboratory tests or medications.

The purpose of the medical record is to enhance patient well-being and quality of care. Generally, the patient is the best judge of his or her best interests. Some patients might regard breaches of confidentiality as more threatening than the risk of suboptimal care resulting from incomplete medical records. Thus, a patient's informed preferences to exclude sensitive information from the medical record should be respected if feasible. Many psychiatrists keep their detailed psychotherapy notes separate from the rest of the patient's medical record.

OVERRIDING CONFIDENTIALITY TO PROTECT THIRD PARTIES

Overriding patient confidentiality might prevent serious harm to third parties, as the following case illustrates. HIPAA expressly permits these exceptions to confidentiality, which are often required by state law.

CASE 5.3 Risk of HIV transmission.

A 32-year-old accountant reveals to his physician that he had a positive test for HIV antibodies at an anonymous testing center. He asks his physician not to disclose the test results to anyone, because he is concerned about losing his job and health insurance. His physician encourages him to notify his wife so that she can be tested. After several discussions, the patient continues to refuse to notify his wife or allow others to do so. He declares, "If she finds out, it would destroy our marriage." Should the physician notify the wife despite the patient's objections?

The ethical guideline of nonmaleficence requires both patients and physicians to avoid harming other people and to prevent harm to others. Infected persons have a moral duty not to harm others and to notify persons whom they have placed at risk. This duty is particularly strong when trust is expected, as in marriage. The common law may also impose on infected persons a legal duty to notify partners whom they place at risk (13). In Case 5.3, the patient abrogates this responsibility. In addition, physicians might need to override confidentiality to prevent serious harm to third parties in some circumstances, as we discuss next.

JUSTIFICATIONS FOR OVERRIDING CONFIDENTIALITY

The balance between preventing harm to third parties and protecting confidentiality is ultimately set by society through statutes, public health regulations, and court decisions. Setting this balance as public policy allows all points of view to be represented and is preferable to decisions by the individual physicians in their offices or at the bedside. Laws on confidentiality vary from state to state. In general, exceptions to confidentiality are warranted when all the following conditions are met (Table 5-2):

- The potential harm to identifiable third parties is serious.
- The likelihood of harm is high.
- There is no less invasive, alternative means for warning or protecting those at risk.
- Breaching confidentiality allows the person at risk to take steps to prevent harm.
- Harm to the patient resulting from the breach of confidentiality is minimized and acceptable. Disclosure should be limited to information essential for the intended purpose, and only those persons with a need to know should receive information.

TABLE 5-2**Situations in Which Overriding Confidentiality Is Warranted**

The potential harm to third parties is serious.
 The likelihood of harm is high.
 No alternative for warning or protecting those at risk exists.
 Breaching confidentiality will prevent harm.
 Harm to the patient is minimized and acceptable.

In these circumstances the overall harm to the third parties at risk is judged to be greater than the harm to the index case resulting from overriding confidentiality (14).

Confidentiality can be overridden in several ways. Physicians need to distinguish reporting to public officials, partner notification by public health officials, and direct warnings to third parties at risk.

REPORTING TO PUBLIC OFFICIALS

In certain situations physicians are legally required to break confidentiality and to report the name of a patient to appropriate public officials (Table 5-1).

Infectious Diseases

Physicians, clinical laboratories, and hospitals are required to report to public health officials the names of patients with specified infectious diseases, such as tuberculosis and gonorrhea. Such reporting allows accurate epidemiologic statistics and public health planning and facilitates partner notification. The goals of monitoring diseases and planning programs can be achieved without reporting the names of infected persons. However, partner notification requires reporting by name.

SPECIAL PROTECTIONS

Certain conditions might be considered particularly sensitive because the risk of stigma and discrimination is believed to be greater than in other illnesses. Earlier in the HIV epidemic, many states passed laws to strengthen the confidentiality of HIV test results and to require written informed consent for HIV testing (15). Furthermore, although the Centers for Disease Control and Prevention (CDC) required AIDS cases to be reported, HIV infection was not reportable in many states (16). Alternative test sites were established in which people could be tested for HIV antibodies anonymously.

Recently, reporting of HIV infection to public health officials has become more similar to reporting of other infectious diseases. Reporting of persons with HIV infections by name is now required in most states and has been recommended nationally (17-19). There are several reasons for this policy change (17,19). Because prognosis has improved dramatically with highly active antiretroviral therapy, there is a stronger rationale for partner notification. Also, reporting only AIDS cases gives an inaccurate picture of the epidemic, compromises public health planning, and leads to inequitable distribution of funding based on caseload. However, anonymous testing is still permitted (20).

IMPAIRED DRIVERS

Many states require physicians to report to the department of motor vehicles persons with specified medical conditions that impair their ability to drive safely. Such conditions include epilepsy, syncope, dementia, sleep apnea, and other conditions that impair consciousness (21-23). Even if the

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underlying condition is treated, the patient might not be able to drive safely. For example, after placement of an implantable cardiac defibrillator, about 10% of patients experience syncope or near-syncope associated with defibrillation in the first year (24). The physician's role is not to stop the patient from driving or to decide whether the patient should be permitted to drive. Such determinations are properly made by the department of motor vehicles. The physician only informs officials of persons who warrant investigation. Reporting is particularly important for patients who drive commercially and present greater risks because they spend more hours on the road, are responsible for third parties, and drive heavy vehicles (23,24).

Injuries Caused by Weapons or Crimes

Almost all states require physicians to report injuries involving a deadly weapon or criminal act (25). The rationale is to protect the public from further violence.

PARTNER NOTIFICATION BY PUBLIC HEALTH OFFICIALS

In partner notification, persons at risk for an infectious disease are warned that they have been exposed. More partners are notified when public health officials carry out the notification than when patients do it themselves (26). In the AIDS epidemic, the term *partner notification* has replaced the traditional term *contact tracing*. Many contagious diseases, such as tuberculosis, are spread through aerosolized particles and can be transmitted by casual contact. Many casual contacts might be located without the cooperation of the index case, as by going to the index case's workplace.

"Mandatory" Partner Notification

For all practical purposes, partner notification in HIV and other blood-borne and sexually transmitted diseases must be voluntary (27). In many cases sexual or drug-sharing partners cannot be identified without the infected person's cooperation. If patients do not wish to cooperate, they can deny that they have partners or give inaccurate names and addresses. Attempts to make partner notification "mandatory" are misguided and counterproductive. Any perception that partner notification programs are punitive or disrespectful to index cases will further reduce cooperation.

Minimizing Harm during Partner Notification

In partner notification, partners should only be told that they have been exposed. The identity of the index case is not revealed (27). However, index cases cannot be promised anonymity, because partners can often infer their identity.

WARNINGS BY PHYSICIANS TO PERSONS AT RISK

In addition to notifying public officials, physicians might have a legal duty or the legal option to warn identifiable persons whom a patient places at risk (Table 5-1).

Violence by Psychiatric Patients

Physicians have a legal responsibility to override confidentiality to protect persons who are potential targets of violence by psychiatric patients (*see* Chapter 42). The landmark Tarasoff ruling declared, "Protective privilege ends where public peril begins (28)." Although many physicians believe that the law requires them to *warn* the persons who are potential targets, in fact the law requires a broader duty to *protect* the person who is a potential target from harm (29). This duty to protect persons who are targets might involve more intensive therapy, voluntary or involuntary hospitalization, convincing the patient to give up weapons, or notifying the police. Many states have similar requirements.

INFECTIOUS DISEASES

Courts might require physicians to warn patients with infectious diseases to take precautions to prevent their infectious disease from afflicting others (30). In addition, some courts require physicians

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to notify identified persons whom their infected patients place at risk (31,32). These rulings involved conditions such as hepatitis, tuberculosis, and Rocky Mountain Spotted Fever. Generally, physicians can fulfill this duty by notifying public health officials.

PHYSICIAN JUDGMENT

Although society has set legal requirements for public health reporting, physicians might still face dilemmas. As in Case 5.3, patients might ask physicians not to disclose information as required by law. Such a patient might promise to use condoms but refuse to notify his wife. Physicians might be sympathetic to such requests. In one study more than 60% of physicians were willing to allow a patient with gonorrhea to tell his wife that he had nonspecific urethritis (33). This strategy, however, is ethically problematic. The wife would not know the nature of the infection, her long-term risk of infertility, or the need for follow-up. In addition, feminists object that male physicians apply an unfair double standard, protecting the man's interests rather than the woman's health and autonomy.

Some jurisdictions explicitly give physicians discretion on partner notification in some situations (34,35). For example, in California physicians are *permitted* but not *required* to notify partners of HIV-infected patients (or notify public health officials) (36). Physicians who decide to notify cannot be held liable in civil or criminal proceedings (36).

Sound medical ethics might require notification even though the law does not. In Case 5.3, physicians should try to persuade the patient to agree to public health measures. The physician also can try to elicit patients' concerns and address them. For example, if patients are concerned about job discrimination, physicians can reassure them that the Americans with Disabilities Act protects patients from discrimination based on illness. Physicians should notify patients if reporting will occur over their objections and take into account requests about carrying out the reporting. For instance, a patient may choose to notify his wife before public health reporting.

OVERRIDING CONFIDENTIALITY TO PROTECT PATIENTS

In several situations physicians are required to override confidentiality to protect the patient rather than third parties (Table 5-1). In these situations the ethical justification for intervening is that patients might not be able to protect themselves. The federal health privacy regulations allow physicians to comply with state requirements for such reporting.

CHILD ABUSE

All states require health care workers to report suspected child abuse or neglect to child protective services agencies (37). The parents' privacy is overridden in order to protect vulnerable children from a high probability of serious harm. More than 1,000 children die of neglect and abuse each year; most are under the age of 5 (37). Health care workers might be the only people outside the family to have close contact with preschool children. Physicians need only reasonable suspicion of abuse and neglect, not definitive proof, to justify a fuller investigation. To encourage reporting, most states grant immunity from civil and criminal liability when reporting is done in good faith. Intervention might enable parents to obtain enough assistance and support to prevent further abuse. In extreme cases the child might be removed from parental custody. In evaluating possible child abuse, pediatricians should treat parents with respect, keeping in mind that most parents are trying their best to deal with the challenges of childrearing.

ELDER ABUSE

Most states require health care workers to report cases of elder abuse to adult protective services (38). The goal is to identify persons who are incapable of seeking assistance on their own and to offer them help. Elderly persons who are dependent on their caretakers might be unwilling or unable to complain about physical or psychological abuse or neglect (39). Patients might not be aware of available in-home supportive services or might feel intimidated by caretakers. Patients might fear that if they complain, they will be worse off, perhaps placed in a nursing home. Most

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abusers of elderly persons are family members who are overwhelmed by caring for a frail elderly person. Thus, reporting and intervention might provide resources that allow the elderly person to continue to live safely at home. Elderly persons who are truly capable of making informed decisions and free of intimidation or coercion are free to decline offered assistance.

Specific laws for reporting elder abuse vary from state to state. Generally, reasonable suspicion of abuse is sufficient to trigger reporting. Health care workers must report abuse only when they obtain information about a patient in their professional roles. Thus, although physicians as private citizens may report an elderly neighbor whom they suspect is abused, they are not *required* to do so. Health care workers receive legal immunity when they make reports of suspected abuse in good faith.

DOMESTIC VIOLENCE

Domestic violence is physical, sexual, or psychological assault against intimate partners. The vast majority of people who are assaulted are women. Many states require health care workers to report suspected domestic violence or abuse (25). Persons who are assaulted often are unable to take steps on their own to escape further violence. Reporting is intended to protect the person assaulted and to hold perpetrators of violence accountable. However, it might be ineffective or even counterproductive (25). Mandatory reporting might put battered patients at risk of retaliation from their assailants. The police and courts often respond poorly to reports of abuse. Thus, physicians might face conflicting obligations: a legal mandate to report and the patient's desire not to report the abuse. Physicians should provide emotional support and refer patients to shelter, legal services, and counseling. Particular concerns about an increased risk of violence should be communicated to the police when making a report (25). Whenever possible, physicians should promote the abused person's autonomy—for example, respecting a request to delay reporting until the person can find shelter.

In conclusion, physicians should maintain confidentiality unless there are compelling reasons to override it. Physicians need to understand why society has determined that in some situations it is appropriate to override confidentiality. In some situations the law provides clear guidance for physicians about confidentiality. However, the law might be silent about other situations, or it might defer to the judgment of physicians. Finally, the physician might want to go beyond the law in some circumstances. Even if public health reporting is required by law, it is respectful to tell patients that reporting will occur, obtain their agreement if possible, and take steps to address their concerns and minimize harm to them.

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Avoiding Deception and Nondisclosure

Children are taught to tell the truth and avoid lies. In clinical medicine, however, the distinction between telling the truth and lying can seem simplistic. Even doctors who condemn outright lying might consider withholding a grave diagnosis from a patient or exaggerating a patient's condition to secure that patient's insurance coverage. This chapter analyzes the ethical considerations regarding lying, deception, misrepresentation, and nondisclosure. Such actions might mislead either the patient or a third party, such as an insurance company or a disability agency.

DEFINITIONS

The following case illustrates some ways physicians might provide misleading information.

CASE 6.1 Family request not to tell the patient the diagnosis of cancer.

A 70-year-old Cantonese-speaking man with a change in bowel habits and weight loss is found to have a carcinoma of the colon. The daughter and son ask the physician not to tell their father he has cancer. They say that patients in his generation are not told they have cancer and that if he is told, he will lose hope.

Physicians might provide misleading information in different ways.

Lying refers to statements (a) that the speaker knows are false or believes to be false and (b) that are intended to mislead the listener. For example, the physician might tell the patient that the tests were normal.

Deception is more broadly defined than lying, and it includes all statements and actions that are intended to mislead the listener, whether or not they are literally true. An example would be telling the patient that he has a "growth," hoping that the patient will believe nothing is wrong. Other techniques used to mislead people include employing technical jargon, using ambiguous statements, omitting important qualifying information, and presenting misleading statistics.

Misrepresentation is a still broader category, including unintentional as well as intentional statements and actions. The statements might or might not be literally true. Unintentional misrepresentation might result from inexperience, poor interpersonal skills, or lack of diligence or knowledge. For instance, a physician might not tell a patient that he or she had cancer because the physician did not receive the biopsy report.

Nondisclosure means that the physician does not provide information about the diagnosis, prognosis, or plan of care. For example, a physician might not tell a patient that he or she has cancer unless the patient specifically asks.

Many writers on medical ethics use terms such as "truth-telling" or "veracity." This book, however, uses the terms *deception* and *misrepresentation* because ethically difficult cases usually involve deception or nondisclosure rather than outright lies.